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ABSTRACT

This guide represents part of AARP's comprehensive consumer education effort in the area of long-term care. The purpose of the guide is to provide information for consumers as they look for a nursing home, arrange for admission, and adjust to life in the home after admission. Section 1 introduces the guide. Section 2 describes how to assess needs, including the payment for nursing home care. Section 3 discusses admissions. Section 4 discusses entering and adjusting to nursing home life. Structure, services, and staff are described in section 5. Section 6 describe getting what an individual needs in a nursing home, including the use of an ombudsman or the state licensing and certification office. Section 7 discusses issues of poor care or abuse. Appendix A provides a checklist for selecting a nursing home, including sections on location; general physical characteristics; attitudes and atmosphere; safety; medical, dental, nursing, and dietary services; pharmaceutical services; food services; social services and resident activities; residents' rooms; transportation; and financial considerations. Appendix B provides the nursing home residents' bill of rights as determined by federal legislation. Appendix C describes nursing home staff required by federal regulations. Appendix D lists addresses and telephone numbers for the National Association of State Units on Aging. Appendix E lists addresses and telephone numbers for state long-term care ombudsman offices. Appendix F lists addresses and telephone numbers for state agencies on licensing and certifications. Appendix G lists 11 publications and 5 organizations as resources. (CML)

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NURSING HOME LIFE:

A GUIDE FOR RESIDENTS AND FAMILIES

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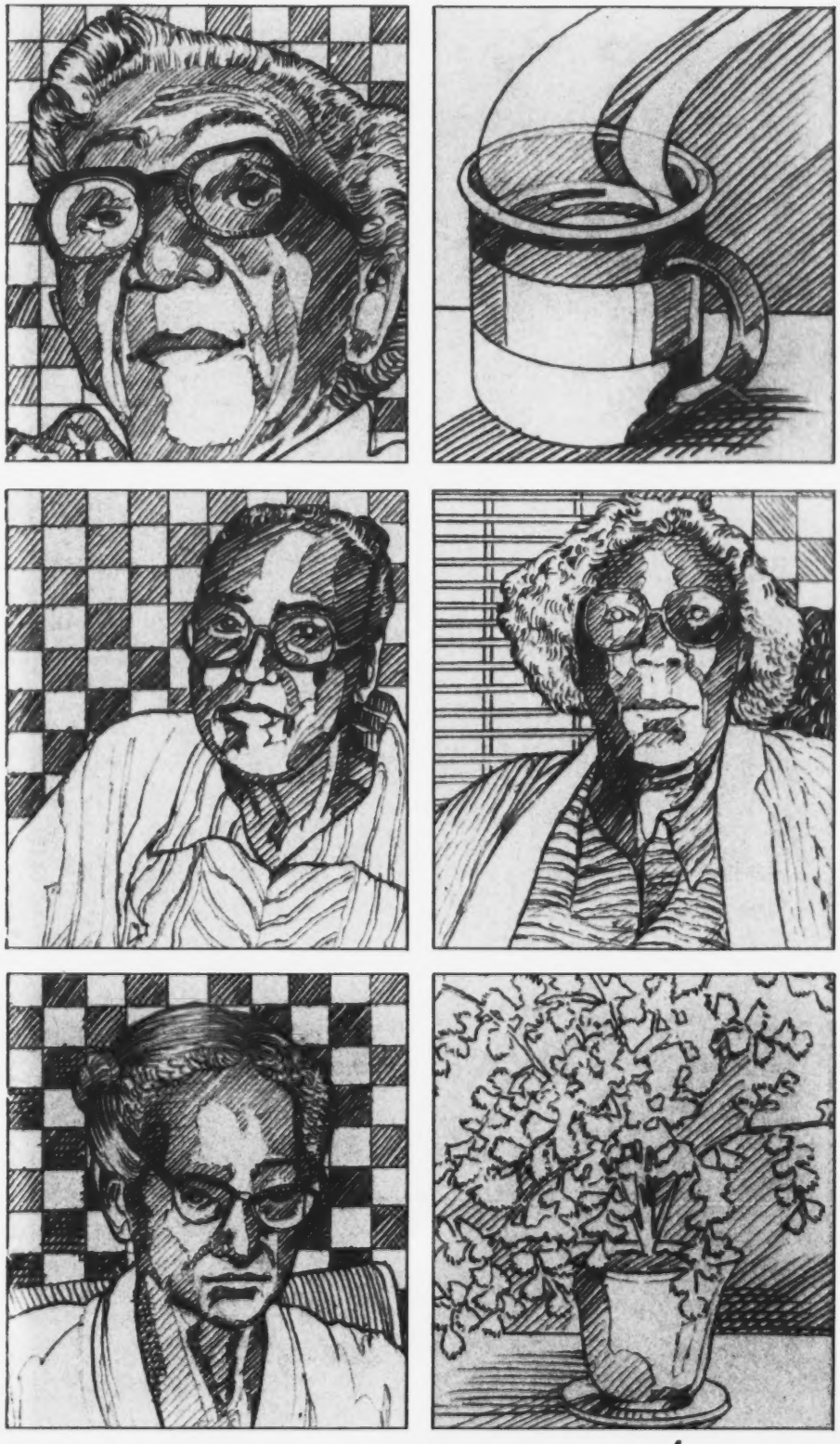
Through its Women's Initiative, AARP has committed itself to assuring availability, accessibility, and quality of long-term care. Recognizing that women generally live longer than men and are particularly vulnerable to chronic conditions requiring long-term care, AARP has undertaken to provide information that will permit informed decision making to meet individual, changing needs.

This guide represents part of a comprehensive consumer education effort in the area of long-term care. It is designed to assist you in evaluating your needs and how to best cope with the adjustments of nursing home life.

It is our hope that this overview will provide you with some direction in making important decisions for yourself or your loved ones and as a result, help you become better consumers.

Nursing Home Life: A Guide for Residents and Families was produced by the American Association of Retired Persons as an educational service to members and other older persons. Use of this publication for commercial purposes is prohibited.



NURSING HOME LIFE:

A GUIDE FOR RESIDENTS AND FAMILIES

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ACKNOWLEDGMENTS

Health Advocacy Services, a section of the American Association of Retired Persons Program Department, interviewed nursing home residents and their families in order to obtain, first hand, accounts, experiences, and insights into nursing home life. We wish to thank the following individuals and facilities for their cooperation in responding to our requests for interviews.

Individuals Interviewed: Residents, Families and Friends

Mrs. Helen Ainsworth
Mrs. Dorothea Bargus
Mr. Bernard Barnes
Mr. and Mrs. George Brown
Mr. and Mrs. Charles Burr
Mrs. Barbara Carter
Mrs. Lou Ellicot
Mrs. Esta Ehrhart
Miss Margaret Gibson
Mr. Harold Graves
Mrs. Alice Kendall
Mrs. Doris Lee
Mrs. Lucille Linton
Mrs. Elizabeth McKee
Miss Dorothy Miles
Miss Alicia Powell
Mr. Joseph Poskus
Mrs. Irene Preston
Mrs. Ann Simpich
Mrs. Josephina Sparks
Dr. Orman Street
Mrs. Evelyn Taylor
Mr. G. A. Thornton
Mrs. Mattie Thornton
Mr. Lee F. Towns
Miss G. J. Tulloch
Mrs. Jane Vines
Ms. Janet Wells
Mrs. Rosa Williams

Nursing Homes in Which Residents Were Interviewed

Berlin Convalescent Center
Rural Route 3
Box 6684
Barre, VT 05641

Hillhaven Nursing Home
3210 Powder Mill Road
Adelphi, MD 20783

Madison Manor Nursing Home
5801 42nd Avenue
Hyattsville, MD 20781

Stoddard Baptist Home
1818 Newton Street, N.W.
Washington, DC 20010

Tranquility Nursing Home
Randolph, VT 05060

Washington Center for Aging Services
2601 18th Street, N.E.
Washington, DC 20016

The Washington Home
3720 Upton Street, N.W.
Washington, DC 20016

AARP appreciates the guidance and support from the following individuals in the development of this guide:

—Sarah Greene Burger, R.N., MPH

—Barbara Frank, Associate Director, National Citizens Coalition for Nursing Home Reform, Washington, D.C.

—Anne Hart, Ombudsman, District of Columbia, Legal Counsel for the Elderly, Washington, D.C.

FOREWORD

Nursing homes are often not the first choice for individuals in need of long-term care services. For some, however, nursing homes provide the type of care which will best meet their needs and assure their safety and well-being.

Making the decision to seek nursing home care and selecting a home can be a difficult, often emotional, process. In addition, the transition from life at home, to life in a nursing home can be challenging for both residents and family members. Such a change requires time to make adjustments. Older people living in a nursing home find it necessary to cope with the difficulties of adapting to institutional living.

The purpose of this guide is to provide information which will be of value to consumers as they search for a nursing home, arrange for admission and adjust to life in the home after admission. In preparing this guide, 29 individuals, both residents and family members, were interviewed. Their thoughts and ideas appear throughout the booklet. We hope that their experiences and wisdom will be of value to current and future nursing home residents and their families.

While there were a number of problems encountered and concerns expressed by the residents, there were also many benefits gained from living in a nursing home. Residents expressed relief in having someone to help them with daily activities; others established new friendships; and some, through rehabilitative therapies, acquired renewed strength in their physical capabilities and improvement in their emotional well-being.

By learning of the experiences and coping skills acquired by others, we hope consumers will be better able to face the challenges and adjustments nursing home life may present.

Horace B. Deets
Executive Director

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INTRODUCTION

She has a favorite nurse. She'll walk in and say, 'Well, old lady, are you ready to get out of that bed now?' Mother loves that because she knows they don't mean anything. She'll walk in and put her arms around her when she asks her that, or she'll bend over and give her a kiss and then she'll talk to her. . .

The decision to seek nursing home placement can be a difficult experience for everyone concerned. It can mean a loss of a certain life style and of things which are important to a person and which helps define one as an individual: one's own home, personal possessions, and daily routines.

Once a decision has been made for you or a relative to enter a nursing home, it will be important to select the home that is right for you, and to learn how to adjust to living there.

Some people who need nursing home placement have the luxury of time and the availability of several nursing homes with vacancies from which to choose. For many, however, the need for nursing home placement is more immediate, and the availability of openings in nursing homes scarce, leaving little opportunity for planning and selecting.

This guide is intended to assist those consumers who are both searching for a nursing home that best meets their needs, and those who are trying to adjust to life once admitted to a home. It is also our hope that interested, concerned citizens will find this guide useful as they volunteer and assist residents who do not have family or friends to turn to for support.

By knowing ahead of time about how to look for a facility which best meets your needs, by learning what to expect, and how to cope with nursing home placement, individuals can have more control over their lives and will be better able to advocate for themselves and their loved ones.

The American Association of Retired Persons (AARP) talked to residents, their families and friends to learn what it is like to live in a nursing home. Their experiences and comments have been included in the guide. Twenty-nine individuals, both residents and family members, were interviewed and asked to discuss at length how they came to live in a nursing home and what it is like for them to live there, what is good and not so good about the arrangement, and how they have coped with the changes in their lives.

To prepare this handbook, residents in all types of nursing homes were interviewed—nursing homes that were:

- Large and small, from 25 to 300 beds;
- Located in urban, suburban, and rural settings;
- New and older; and
- Intermediate care and skilled care facilities.

Residents were aged from 45 to 101 years—two also had their children in nursing homes. Some were impoverished, others were of moderate means, and some were wealthy. They were male and female, black, white, and Hispanic. Some were selected by the nursing home staff to be interviewed, others were not.

The guide is divided into the following sections:

- Assessing Your Needs
- Admissions
- Rite of Passage: Entering and Adjusting to Nursing Home Life
- Structure, Services, and Staff
- Getting What You Need in a Nursing Home
- Issues of Poor Care and Abuse
- Comparison Checklist
- Appendices.

ASSESSING YOUR NEEDS

If they gotta go to a nursing home, that is where they should go. . . where somebody will watch over them and care for them, and have an interest in them. They do here.

A nursing home is a godsend to people who are left alone, or their family don't take care of them properly. I don't know where they would live if there wasn't a nursing home.

Nursing homes perform a vital function in the range of health care services they provide; however, they are not always the appropriate or necessary choice for all older persons having difficulty living in their own homes. Although they become a permanent home for many, they are often utilized as a temporary or short-term option.

The first step in considering nursing home care is to assess your needs and evaluate your options. Many communities have a range of services available to assist you in your own home. Your local Office on Aging and your physician are community resources that can help you explore existing home care options. The phone number for the Office or Department of Aging in your area is listed in the phone book in the "Government" section. See the Appendices for further information and for a list of resources.

What are the circumstances which necessitate nursing home placement? Here is what some residents said:

I didn't decide that I needed a nursing home, the doctor decided. I wasn't frightened because I knew I couldn't do much of anything for myself.

A year ago today he had a quadruple bypass. . . that is why I ended up in the nursing home. I had fallen three times in a row. . . He was afraid I would fall sometime when he wasn't there.

She needs constant monitoring nutritionally and for the unending pills she takes. She frequently requires oxygen. If you have unlimited money you can replicate it at home. I had the doctor tell her.

We decided it would be better if I came to a place like this. I could have gone home, but my husband and I decided together and separately that it wouldn't work at home. . . I needed to learn to dress myself and walk again.

I was living alone on the farm when I took sick. . . I didn't have nothin'. . . nowhere to go. . .

I realized I couldn't be there 36 hours a day. I couldn't keep her dry as well as these people do. . .

He had Alzheimer's disease. One night mother found him in the bedroom with a gun looking out at people who were going to a meeting. That's when we knew something was really wrong. I had to hire him a lawyer and a guardian.

Looking at these comments, one sees the variety of circumstances in life which may lead to nursing home placement. A number of people may be involved in making the decision: the prospective resident, family members or friends, a doctor, a social worker, or hospital discharge planner.

One important factor in arranging nursing home placement is called the "level of care." Knowing the level of care that you or a relative needs is necessary to determine the type of nursing home which is required to meet your needs.

There are three levels of care:

Skilled Nursing—is for persons who need intensive care, 24-hour-a-day supervision, and treatment by a registered nurse under the direction of a physician.

Intermediate Care—is suitable for persons who do not require round-the-clock nursing, but who are not able to live alone.

Custodial Care—is suitable for many persons who do not need the care of a practical nurse but need supervision (help with meals, personal hygiene, and the like).

The level of care required is determined by your physician. In addition, many states require and conduct pre-screening of potential nursing home residents to determine the level of care needed. Your local social service agency or the admissions person at any nursing home can direct you to the agency that makes this determination.

In assessing your situation, you will also need to consider your financial situation and personal resources. The issue of financing nursing home care was one of great concern to many residents and families interviewed:

I worry about money. . .

I still own my own home now, but it looks like I'm going to have to sell it to stay here.

She went in May, and in June we figured she run out of her money and assets by September.

Money makes a difference. With enough money, you can do almost anything.

Paying for Nursing Home Care

Nursing homes charge a basic daily rate for a package of services which they provide. Some services may not be included in that package and may cost extra.

A nursing home may be financed in a variety of ways:

Personal Resources—Your relatives' or your own ability to pay nursing home expenses out-of-pocket will play a major role in whether a home is willing or able to accept you or your relative as a resident. Consequently, the amount of your personal resources—savings, income, value of real estate, insurance benefits—is an important factor. Since nursing home care is so costly, many people enter a home paying for care with their own income and savings, but must apply for Medicaid to cover the cost of their care once their savings are depleted. (See description which follows.)

Medicare—Contrary to popular belief, Medicare and medigap policies contribute little to nursing home costs. Medicare, the health insurance program for people over age 65, and disabled people, will pay most of the costs for up to 150 days each calendar year for care in a nursing home which provides skilled nursing care. Prior hospitalization is no longer required. Beneficiaries are required to make a co-insurance payment ($20.50 in 1989) per day for the first eight days only. Residents must need skilled services on a daily basis to be eligible for these benefits. Medicare does not pay for intermediate care. Eligibility requirements for Medicare include: (a) anyone age 65 or over who is eligible for Social Security or Railroad Retirement benefits, whether of his or her own record or that of a spouse; and (b) individuals under 65 who are eligible for Social Security disability benefits or have kidney disease that requires dialysis.

Private Insurance—There are also private long-term care insurance policies available on a limited basis which vary in the coverage they provide and must be carefully examined before purchase. A number include some type of nursing home benefit but it is important to note specific features such as a prior hospitalization requirement, whether there is coverage for custodial care or if custodial care is covered only after receipt of skilled care. It is also important to look at the amount and length of the benefit, waiting periods, exclusions and other requirements.

Medicaid—Medicaid coverage for nursing home care is available to eligible low-income individuals, and to nursing home residents who have exhausted their resources paying for nursing home care. Under Medicaid, states provide services to the aged, blind, or disabled poor. An applicant must be a citizen or resident of the United States and must meet state income or resource limitations.

Since the daily rate paid by Medicaid is significantly lower than the rate homes can charge private-pay residents, Medicaid residents are generally less preferred by nursing homes. Moreover, some homes do not accept anyone as a resident if they rely on Medicaid for payment and will not retain residents whose personal resources have been depleted and who become Medicaid recipients.

Federal and state laws and regulations governing the program provide protection to Medicaid beneficiaries against discrimination. Medicaid beneficiaries often face discrimination in admissions to nursing homes or in the services they receive, however.

Federal Medicaid standards for nursing home care and state licensing standards prohibit some of these discriminatory practices but do not address other common practices. The regulations do include provisions related to admissions, services and charges, and continued stay in the home if personal resources are exhausted and one becomes eligible for Medicaid.

One rule some states use to determine Medicaid eligibility is known as "deeming." While a couple lives together, one spouse's income and assets are considered (deemed) available to pay the other spouse's health care bills. Therefore, a Medicaid applicant must deplete a spouse's income and assets before receiving coverage.

The federal government states that if a spouse's name appears on a pension check for example, even if the check is considered to be joint income, then that asset is available to the Medicaid applicant to pay for care. Several states have addressed this issue by splitting income or assets in half when determining a spouse's Medicaid eligibility.

Impoverishment of the spouse of a nursing home resident who is on Medicaid is not uncommon. This is due to Medicaid's treatment of income. With several exceptions, all of an institutionalized person's income must go to pay for his or her nursing home care. Consult the state nursing home ombudsman or a lawyer for further information about specific policies in your state as they relate to spousal assets and income.

Under the new catastrophic care legislation, states must allow the spouse remaining at home to retain (from the couple's income and assets) at least $786 per month in income and at least $12,000 in liquid assets or resources (in addition to the couple's home). These amounts will increase each year. This provision takes effect September 30, 1989.*

***Note of Caution:** In a few states that currently have very liberal laws and practices, these could actually leave the spouse with fewer resources than would have been retained under current law. However, the Act allows states the option to increase the amount of income and assets that can be kept by the spouse remaining at home.

In addition to assessing your medical and financial needs and abilities, you will also need to assess the importance of other factors. For instance, these factors should be considered:

- The need for rehabilitative therapies, such as physical or occupational therapy;
- Participation in social or religious activities;
- Frequent contact with other mentally alert and cognizant residents; and
- Proximity to allow frequent visits by friends and family members.

If these or other issues are important to you, you will have to determine how to take care of them in any nursing home you choose.

If you are looking for a home, plan a visit to the homes you are considering after assessing your situation. It is impossible to know what a nursing home is really like or if it will meet with your approval unless you have had an opportunity to see it, meet the staff, and to observe the residents and resident/staff interactions and activities. It is also very important to include the prospective resident in the decision-making process to the greatest extent possible. Prior to visiting a nursing home, think of all possible questions to ask, write them down and discuss them with the administrator on your initial visit. Some mistakes might be avoided, as one relative stated:

I have seen a lot of nursing homes. I had to put my mother in one five years ago for three weeks. I made a lot of mistakes that I wouldn't make now. I know what to ask for. You just have to ask the right questions...

The information included in this guidebook can be useful to those looking for a home and to those residents and families adjusting to nursing home life. There is a checklist in the Appendix to use as a guide when selecting a nursing home. In addition, there are numerous booklets and guides available which specifically focus on nursing home selection. For further information, refer to the Appendix for a list of Selected Resources, or contact your local Office on Aging, or ombudsman. (See lists in the back of the Guide.)

ADMISSIONS

When making plans for admission to a nursing home, there are a number of important items to keep in mind.

General Policies

Each home has its own policies and procedures for a variety of issues such as visiting hours, use of resident furniture and possessions, and many other issues. A copy of the home's policies should be available on request. Many policies may not be formally listed and one might not think of them or learn of their existence until after admission.

Some specific policies to check would include:

- The use of personal possessions and furniture
- Availability of foods at times other than mealtime
- Special diets
- Room assignments and changes
- Reserving a bed if resident is transferred to the hospital
- Visiting hours
- Emergency procedures
- Self-care
- Phone calls
- Access to personal funds.

Another factor to consider is whether your personal physician would be willing and able to provide services at the nursing home. Some homes may try to restrict physicians who are not affiliated with the home from providing care. This is illegal in most states and, in general, you have the right to retain use of a private physician as long as he or she complies with the policies of the home and the regulations of the state. However, physicians may find a home too inconvenient to visit. Here are two observations:

She got a new doctor when she went to the nursing home. Her own doctor is an excellent medical man but doesn't make house calls to the nursing home.

My advice to anybody who is going into a nursing home is that they retain a link with a private physician.

Be sure to discuss this issue with the administrator when visiting the home. Also, explore the nursing home's arrangement for transporting ill residents to the hospital and the hospitals to which residents are taken.

The Admissions Contract

The nursing home may refer to the contract by one of several names: the financial agreement, entrance contract, admissions agreement, etc. Whatever the terms, it constitutes a legal contract between the nursing home and resident, spelling out the conditions under which the resident is accepted.

The contract should state the costs, services included, legal responsibilities, and any other matters of a legally binding nature. Before signing, be sure you understand it completely. Feel free to ask questions about the contract and to consult a lawyer or the ombudsman if anything is unclear or questionable.

Contracts requiring a resident to continue to pay privately, even if personal resources are exhausted and he or she becomes eligible for Medicaid, have been ruled illegal by attorneys general in several states. These contracts, called "duration of stay" contracts, require payment at a certain rate for a designated period of time.

Federal law makes these contracts illegal effective October 1, 1990.

Often families take extreme measures to continue private payment, for fear that their relative will be evicted or mistreated. Some contracts may contain clauses which are not legal such as "waivers" of responsibility for lost possessions or injury, or may request "blanket" approval for certain treatments. Again check with a lawyer or ombudsman about such conditions.

Mandatory Contributions

Nursing homes may not require Medicaid-eligible persons to make contributions, donations, or gifts as a condition of admission or continued stay in the nursing home. If this occurs, refuse to contribute, informing the home of your understanding that such a practice is illegal, and contact your local ombudsman. The federal Medicaid law does not provide protection for private-paying individuals from whom nursing homes may require such a donation, contribution or gift.

Responsible Party Signatures as a Condition of Admission

Quite often, nursing homes ask that a resident's relative or friend sign an admissions contract agreeing to serve as "responsible party." There is no clear-cut federal definition of a responsible party's legal responsibilities and few states provide a legal definition. Nursing homes may not hold anyone else responsible for a Medicaid beneficiary's bills, unless that person has legal access to and responsibility for handling the resident's funds. If you are faced with this situation, consult your local ombudsman for assistance.

Discharge and Transfer When Funds Are Exhausted

Nursing homes may only transfer or discharge residents for a resident's own welfare, for the safety of others, or for nonpayment. When nursing homes sign a contract with the Medicaid program, they agree to accept Medicaid payment as "payment in full." If you or your relative become eligible for Medicaid, then the nursing home will receive payment for care and may not discharge the resident on the grounds of "nonpayment." Nursing homes may not transfer or discharge you when your private funds have been exhausted and you become eligible for Medicaid unless the home does not participate in the Medicaid or Medicare program. (This would mean it is not "certified" to receive Medicare or Medicaid payments and has no other Medicare or Medicaid beneficiaries living in the home.)

Effective October 1, 1989, at least 30 days notice is required pre-transfer or discharge of a resident except in certain cases such as the need for urgent medical treatment. The notice must include notice of right to appeal the transfer/discharge and contact information for the ombudsman. Before transfer for hospitalization or therapeutic leave, written notice regarding the period during which the resident will be permitted to return must be provided.

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Services Covered

Nursing homes bill residents for several types of charges: daily rates for room and board and basic services and any extra charges for services not included in the basic rate, such as therapies, wheelchairs, and dental care. Be sure you know exactly what services will and will not be covered in the daily rate before signing the contract.

States set licensing standards requiring nursing homes to provide a basic set of services to residents (such as nursing and personal care, meals, activities, etc.). These are supposed to be covered by the daily rate. However, many states fail to make clear the scope and extent to which items and services are covered by Medicaid. Nursing homes can levy extra charges for services beyond those covered by Medicaid (e.g., choice of meals, laundry, toiletry items, or special trips). Similarly, private-pay residents should be sure to inquire about extra charges for services not covered in the basic daily rate. There are virtually no limits on how much facilities can charge for these extra services and, for private-pay residents, there are no rules as to what is included in the basic rate and what is extra.

Resident's Rights

In addition, whether you are looking for a nursing home or adjusting to life after admission, you should be familiar with the legal protections for nursing home residents. It is important to know that all nursing home residents are protected—as all citizens are—by existing federal and state laws. In addition to these laws, there are specific federal and state laws, often known as the patient's or resident's bill of rights, which recognize the

vulnerability of nursing home residents and provide additional protection.

Under the federal bill of rights, individuals are entitled to receive information about:

- Rights as residents
- Services offered and charges for those services
- Medical conditions and treatment plans.

Individuals have the right to:

- Dignity, privacy and respect
- Associate freely and privately with persons or groups of their choice
- Receive mail unopened
- Visit privately with spouses.

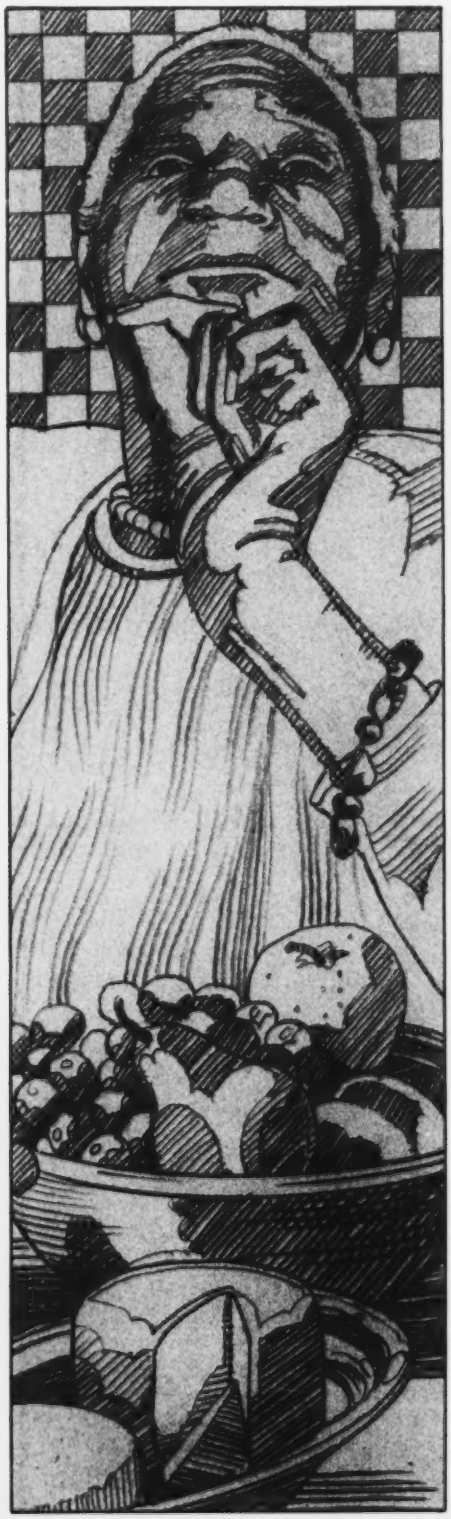
In addition, residents have the right to:

- Be free of abuse or restraint
- Keep possessions and have them secured
- Manage their own finances, or to receive a full accounting if the nursing home is asked to manage them
- Express grievances and make recommendations to the home for improvement
- Know where and how to voice complaints
- Receive a timely notice prior to transfer.

Most states have also enacted a patient's bill of rights. Your ombudsman can provide you with a copy of your state's bill of rights.

It is important for all individuals to act to ensure that residents' rights are respected and protected. Further information about protecting the rights of nursing home residents will be discussed later in this Guide.

RITE OF PASSAGE: ENTERING AND ADJUSTING TO NURSING HOME LIFE



One son said of admitting his mother to a nursing home:

This whole thing was done in a sort of semi- or full crisis atmosphere. I don't know how typical that is.

In fact it is very typical. A resident said,

Society has to form new rituals on this rite of passage. It need not be so terrible.

Why did some of these people enter nursing homes? Who made the decision and how can this be made less frightening?

There are right ways and wrong ways to admit a person to a nursing home. The description of a friend of one resident indicates a poor approach to this matter:

It was a cold, clear day. She sat in the front seat with her mother and I sat in the rear. . . She didn't say a word. She had the doctor for her and I guess he agreed to put her in the home. It was cruel without any preparation. We put her in a room. There was no one there she could be congenial with. She faced the wall. It broke my heart.

There are ways to facilitate admission which lessen the trauma of such a change. For example, one could:

- Talk about the admission in advance
- Visit the home beforehand, if possible
- Involve the prospective resident in making the decision
- Describe the nursing home in detail prior to moving there
- Decide together what to bring to the nursing home
- Get to know the administration of the nursing home
- Maintain good, continued contact with the resident after admission.

Protecting the Resident's Way of Life

Another way to ease the transition and trauma would be to ensure that the prospective resident's accustomed routine or desires are not completely disrupted or abandoned. For instance, you might make a list of all of those routines and habits of the prospective resident and discuss these with the administrator to see if the home is able or willing to accommodate them. Some items to include are:

- Frequency of bathing
- Frequency of hair cuts, hairdressing
- Meal schedule
- Visiting schedule of friends and relatives, including grandchildren
- Religious worship available or other arrangements that can be made.

One resident, in this survey, made it known prior to admission that she had been accustomed to bathing daily and was not told that this would be a problem. After being admitted, however, she found that she was bathed only once a week. After speaking up for herself about what she thought was agreed upon before admission, staff accommodated her and she was then bathed three times weekly.

The Day of the Move

One daughter related this experience about her mother's leaving her longtime home:

It was certainly the most terrible day of my life and it probably was for her, too. She had lived in the place for 25 years. Her friends were there and all her belongings. I don't say she went gladly. I think she went with a feeling there was no viable alternative. She had had an emotionally testing life and has learned to stand out against circumstances.

While some residents enter a home temporarily for a short-term stay, it is still a sad day for most people and sad feelings are normal. Reassure the resident that your love and contact will be maintained.

Many residents couldn't describe their first day in the nursing home because they couldn't remember it. Others could describe it in detail. Many residents told of someone who made that day a little better.

Mary made it welcome for me. She let out love and friendship to different ones that needed it. I was one of them.

If it weren't for Rose, that's the Chief's secretary, and the administrative staff here. . . they broke the ice and they were with me.

An aide was the first person that Mother met after she got to the room. Theresa mentioned later that she felt this special relationship to Mother.

The Admissions Director was helpful. She discussed some of the thoughts I was having at that time.

Sometimes it is another resident who helps on an admission:

When she first came here, they were trying to get her downstairs. I came and talked to her. I said, "Come down." I kept that on and the third morning, I got her to get up and go downstairs for breakfast.

It is important for family and friends to be available the entire day of admission to help settle the resident and provide emotional support. It is very important to continue contacting and visiting the resident regularly after admission.

Supporting the Resident

Friends and family are the most important source of support in adjusting to nursing home life. One resident suggested that a friend give a shower for the potential nursing home resident with appropriate gifts for the new home:

- Carryalls that snap onto a wheelchair or walker
- Sturdy clothing that is easy to get in and out of
- A small change purse
- Pictures of times past or picture frames to put them in
- Cards with personal messages which can be reread at a later date
- Materials for a lifelong hobby.

If the person enters directly from a hospital, then the shower can be given at the nursing home. In either case, a supportive gesture of this nature:

- Makes the resident feel special rather than "cast aside" as one resident described admission
- Encourages relatives and friends to work together for this and future projects with the resident
- Allows the resident to continue being part of the group.

Change Requires Adjustment by Family, Friends, Residents, and Staff

Moving to a nursing home means learning to live in a communal setting after being accustomed to one's own private space. Different aspects of communal life bother people. Here are some comments mentioned by residents:

Now in the morning I'd like to have a cup of coffee. Don't get it until breakfast. At home it was the first thing I did.

My trouble is that I am a smoker. It gives me great pleasure. It's fire regulations. Every time I want a cigarette, I have to ask the nurse.

On the other hand, residents and families also mentioned things gained from moving into a nursing home:

I learned to walk when I got here.

They gave me a bath because I can't do it myself.

They keep your bed nice and clean, pretty good food, people to associate with. We have church every Sunday.

I've gained weight. You better believe it. I was going downhill rather rapidly before. . .

Family members shared these thoughts:

Sometimes you feel guilty about it. Maybe guilty isn't the right word. Maybe it's just plain upset. You feel like you let her down. She spent so much of her life giving to you and you can't give back.

A lot of what goes on with her is nursing care and to be quite honest with you, I was relieved someone else was doing it.

I felt like Mother was dead or something. It was one of the worst nights I ever spent. She was gone. It was horrible.

Mother is healthier and in better shape now than she was when I put her in there.

These individuals have been candid in discussing their feelings. Some have reconciled their feelings better than others. All have coped in some way, often creatively. Here are some experiences:

- One has become a force in the Family Council at the nursing home.
- One visits her mother daily, but is able to walk away when her mother does not know her.
- Another, a long distance away, is in frequent telephone contact with her mother. She has a trusting relationship with the staff. She has hired a social worker to look in on her mother every few weeks.
- Another has not been able to develop a trust in the nursing home, but continues to work toward that end.

In response to questions on coping, residents responded in a variety of ways:

I didn't know anybody right away. It grew better and better. You begin to know people.

A year, at least a year, before it felt comfortable.

For one month that I was here, I never cried so much in my life. I just lay on my bed and cried. . .cried all night.

It wasn't hard to adjust because everyone was so nice.

Gradually, the anger subsided because I am a survivor. I was even fighting myself.

Personal Space

Most people have had some space to call their own, a home, a room, a chair, a particular place outside. Possibly because nursing home life is communal, residents tend to attach themselves to a particular place in the home. This is seen in the dining room where each resident thinks of a particular place as his or hers. This manifests itself in other ways and sometimes causes arguments.

She sits out in the hall by the desk.

Yes, I brought a chair right by the window—sitting right there in that place.

These people come out of church and start to fight with you over a seat. She said, "Get out of my seat. That is my seat you are sitting in." Well, that seat has got no name on it.

Residents, families, and friends must be particularly sensitive to this issue. Often, a particular space is what affords a person a sense of security. If a disagreement occurs between you and another resident, ask for help from someone you trust, such as a social worker or other staff worker.

Privacy

It is very difficult to adjust to receiving personal care for activities which we feel are very private. Remember—resident rights protect the privacy of residents during personal care.

That is one thing that gets me. They don't knock. The head nurses do, the supervisors do, but the others don't. That I resent very much. Even if my door is open, I like them to knock. I did tell them at first, but it went in one ear and out the other.

Unfortunately, your sense of privacy sort of goes out of the window when you are in a nursing home.

Lack of privacy is the first thing I remember on admission. But I should have been used to it from the hospital. This is not a great change. Just make up your mind, this is the way it is.

It's hard to get used to having someone give you a bath. I remember I didn't like for anybody to see me undressed. I'll always remember that, but now I can't help myself, so. . .it doesn't bother me as much as it once did. Gradually wears off, but I don't see as it will ever wear off completely.

You know what really unhinges you is when some large man comes in and takes you to the bathroom. That doesn't seem to faze her. If he is a nice man, he is just like a doctor or nurse to her. It's giving her physical care which she has to have.

These are issues of privacy, pure and simple. Not everyone feels comfortable saying something about the need for privacy, especially a resident who is dependent upon the staff for the basic necessities of life. But remember this is now your place of residence and there are ways residents, families, and friends together can and should address this problem. Sometimes staff may just be unaware of your feelings and just raising the issue may resolve the problem. As a resident, you may want to take one of the following approaches to discuss your concern with a staff person:

- I know you are so busy trying to get all your work done that it is hard to think of little things, but. . .
- I wonder if I might ask a favor?. . .
- It really upsets me when my privacy is not respected; do you think we could figure out a way together to improve this situation?. . .

Use whatever coping mechanism works for you. Try to get the staff to relate to your need for privacy based on their own need for privacy. Other approaches that might be helpful include:

- Families and friends should get to know the nursing assistants since they provide the major care to residents.
- Ask, rather than demand.
- When you do blow up, apologize if you are wrong.
- If you see blatant disrespect, report it to the head nurse.
- Use some humor.

Roommates

Roommates are the rule in nursing homes rather than the exception. This is an advantage for some and difficult for others. Nursing home staffs are interested in having compatible roommates since it is more pleasant for everybody. For instance:

The Assistant Administrator saw me and Geraldine eating lunch together. We got along very well. Geraldine moved in. She is very special.

They say that Mother doesn't relate very well to the other residents. They put her in a room which families visit a lot, so Mother made friendships with the families.

I think as long as I get around as well as I do now, I'm all right, unless I get somebody I just don't like.

We've had two or three roommates. Most of them were unconscious. Yes, I should say it was difficult to be with people so much worse off than you are.

Some residents play a helping role with their roommates even if they don't have anything in common. Still, adjustments and compromises often must be made. Some suggestions for coping with roommates are:

- Allow about six weeks to adjust to your roommate unless the situation is obviously impossible or dangerous.
- Families and friends should get to know the roommate, too. Sometimes this can help residents to get to know one another. Families and friends can also assist residents when differences need to be worked out.
- If things are not working out, ask for suggestions from the nurse in charge on the floor.
- If a change is needed, remember that everyone else has to have a compatible roommate, too. It may be necessary to wait until someone is discharged in order to make a move.

Friendships

Some residents do make friends, *good* friends:

After two years, I got Doris Rogers as a neighbor. She was a wonderful person. We were very close.

Well, here it depends on you. I just made up my mind I was going to find people and I did. I can see where you could go without meeting anybody. . .depends on your attitude and your goal. I know more people because I get around with a motorized scooter.

Others say:

No, you don't make friends. You get acquainted with somebody.

She doesn't feel like making friends when she feels so rotten all the time.

I would like to have someone, someone who would understand. . .a friend of some kind.

There are many reaons that make it difficult for some people to make friends in the nursing home. A resident may be too sick or is shy in a new group of people. Perhaps the death of a friend has created another loss that causes a strain or a person is too angry or feels rejected when adjusting to new living arrangements. Sometimes residents avoid making friends in an effort to protect what little privacy they have or out of fear of being the subject of gossip. Some residents resist developing friendships to avoid becoming like the other nursing home residents, or because they think others have nothing to offer. And some had difficulty making friends before coming to the nursing home. This is why family and friends' visits are so important.

Visits by Family and Friends

Sometimes visits lose their appeal because people run out of things to say. This may mean people don't visit as often after a while.

At home, family members are more relaxed. You visit as time and the rhythm of life permit. Residents, families, and friends tell us what they do during visits:

She loves you to fuss over her. I put powder on her or perfume.

I attempt to read to her. She'll relax and fall asleep sometimes.

My daughter comes once a week. She writes letters for me because I can't write.

Gerald used to go over there and read to himself just to be in the same room as his wife.

Sometimes my husband does have meals with me. He pays ahead of time and gets a tray.

Many older people in nursing homes do not have any family. They have outlived them all. A resident in that situation says:

It would be helpful if everybody's relatives and friends would make it more happy for us. I think that would help out.

Most nursing homes have volunteers who help fill that gap. One resident said of her new friend who volunteered regularly:

I found a friend a year ago and she got me some things. I tried to pay her for them. She saw me and wrote me a note and said she would like to know me better. At Christmas time, she came and brought me some things to wear. It gives me pleasure. . . I consider her my friend.

Visiting schedules should be arranged so the resident can look forward to regular contact. A schedule also helps stagger visits for the resident.

Yes, I wish they would come more often. But they say, "Mama, you just don't understand. We're raising a family, work all day, we just don't have time."

It is important to visit residents year-round. One activity director reported, "most people only discover us at Christmas time."

Visits Between Husband and Wife

Resident rights protect visits between husband and wife. One home hosted a wedding between two residents and then gave them a room with a big double bed. Residents did talk about the need to get away with their spouses for private moments together:

At home, you are more relaxed and not on edge when you want to discuss things. I take him and wheel him down to the reception room if I want to discuss anything personal.

Privacy is respected. When my wife visits, we usually go down to the big dining room. . . practically alone there.

If privacy is denied, use the approaches outlined in the chapter "Getting What You Need in a Nursing Home." Remember you are talking about residents' rights.

Visits with Children

People often question whether children should visit a nursing home. Children should be encouraged to visit. The residents are unanimous in their enthusiasm and pride at having family visit, particularly grandchildren. Here's what some residents and families say:

Sometimes, I take the grandchildren and you should see the smiles. One day I had little Grace there and we were ready to leave. She said, "Grandma, will you bring me back again? We'll have cookies again with great-grandmoms." We got on the elevator, and someone said to me, "What a terrible place to bring a child!" I said, "She doesn't see it that way. She just asked to come back."

. . .Two boys, cute as buttons. Yes, they visit quite often. They sort of start up into my lap and they sort of scramble in there. The older one calls [my wheelchair] a "go ride."

Holidays

Activities with family and friends are important at holiday time. Some residents cannot leave the nursing home for physical or safety reasons and must rely on family and friends to visit them. For those who do not have either family or friends, the activities director and the dietary department team up to create a family occasion:

They keep us busy here at holiday time. The children from the school come in and decorate. Christmas is a lot of fun here.

I spent Thanksgiving with her at the nursing home and they did have a lovely meal down in the dining room.

Visiting Outside the Nursing Home

Visiting outside the nursing home can be important for some people. Very few people like being confined within the same four walls all the time:

I am pretty well devastated still, but I can see some light. Two days ago, my husband came and took me out to lunch in a restaurant. The therapist came along to help us.

We went to their church whenever it was and then went to their house for a party. . . after that, they came and took me out riding.

There is a carpool that picks me up and takes me to church every Sunday.

To get me away from this room once in a while, they got to carry an oxygen tank. But it is only good for two hours. But I can stay out for two hours.

And once a month, I go out there and have dinner, my husband and I. We babysit and they go to the movies. It gives us a chance to be with the grandchildren. We spend the night and have breakfast.

A chance for family and friends to visit together at home away from the public eye, can be particularly meaningful. Points to remember about maintaining contact between family, friends, and residents:

- Visit as often as possible. Work out the times together so it won't become a burden to anyone.
- Don't promise to visit and then not do so, except under emergency conditions.
- Make the time as much like visiting together at home as possible. If you have always played games, do so. If you enjoy just being together in the same room, do that.
- Include each other in everyday life. For instance, one daughter said of her mother:

I've been terribly sick this spring and she started calling me. It was so wonderful.

A son said:

We want to sell her house and I told her. I want her to know we are not doing anything behind her back.

- Bring children and pets as often as possible.
- Urge others to become volunteer/ friends to those without families.

- When possible include other residents in visits. Have a meal together.
- Kiss and hug each other just as you would at home. Let the children snuggle with the residents.
- Make every effort to get out of the nursing home together even for a drive. The staff will help organize this.

Use of a telephone for anyone who can use one is essential to keep contact with the outside world. Whether the family and friends are a few blocks away or a long distance away, the telephone diminishes the sense of isolation.

Coping with Prejudice and Discrimination

The issue of prejudice or animosity towards a person on the basis of race or ethnic group requires some discussion. Racial prejudice is a sensitive issue, but it is an unfortunate reality in our society and within the walls of a nursing home. Whether the source of discriminatory practices or prejudicial treatment originates from the staff or from the residents and their families, such behavior should not be tolerated in a nursing home.

As a resident, you are legally and morally entitled to be treated with respect and dignity by staff. Staff are responsible for providing quality care in the delivery of services to all residents. Staff who are disrespectful to residents or who are not providing care or assistance when needed because of prejudicial feelings towards a resident violate the law, and the resident's bill of rights and the situation must be rectified. If you or a family member is experiencing this type of problem, refer to the section, "Getting What You Need in a Nursing Home," for suggestions.

Similarly, the race or ethnicity of a particular staff person should not result in prejudicial behavior on the part of residents or families. Residents need to rely on staff to care for and respect them, and it will only help matters to reciprocate this respect. If this is an issue about which you or your family have strong feelings, make an effort to discuss your feelings with others and come to a resolution.

Personal Possessions

Although it seems harsh, the best protection against theft is not to bring anything valuable into the nursing home. These people learned the hard way:

She did have a watch taken. It was a very good watch. I replaced it with a very cheap watch.

She had beautiful underthings. All her lingerie was handmade, silk. I lugged laundry back and forth and even then we lost things. We reported it and were told this is par for the course. They were not the kind of things to bring to a nursing home.

The disturbing thing is, of course, that these possessions are some of the things that define a person, making him or her unique. At a time when a person is losing so much, it's hard to say, "No, Mother, you can't bring that because it will be stolen." But it would be worse to lose a treasured item than to leave it safely behind.

Do not think the staff is always to blame because there is a lot of coming and going in a nursing home:

Mrs. Thomas would steal her clothes. I had to get an aide to go through Mrs. Thomas' things and put her clothing back.

Families have come up with some good ideas:

- Don't bring anything valuable into the nursing home.
- If possible, have locked drawers with combination locks for those who can remember the number, or regular locks.
- Carry only a couple of dollars at a time.

Residents with Alzheimer's Disease and Related Disorders

Residents, family, and friends adjust in a variety of ways to the presence of people who are mentally impaired. Here are some comments about this type of resident:

Yes, it was frightening. They would come in. . . I would speak very slowly and say, "Now, that is not your clock. That belongs to my roommate. Please do not take it." He would pick it up, look at it, and put it down.

It took me a while. I didn't do it very well. At first I thought, "What kind of madhouse is this?" And then, it was kind of a Sunday school picnic. Now I have gotten to where I have a little more compassion for them. That was the key, I think, the success of it. You identify with them, and you are on their side.

She had gotten upset and threw her milk on the floor. She gets that way. I guess the best way is to leave her alone. Sometimes, she even says to us, "I'm going to spit on you." I say, "You are not going to spit on me," and she doesn't.

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Noise

Noise is a common element of nursing home life. One of the residents describes noise in the following way:

Nursing homes are not quiet, relaxing places. There is a high level of noise and activity. The staff are not quiet. Laundry carts, tray carts, medicine carts, and there is a lot of traffic in the hall. Other residents, too. Now that we have a special unit for Alzheimer's residents, the noisy ones are up there.

No, the noise don't bother me. You know having had six kids around, you shouldn't let noise bother you.

There are certain places in a nursing home which are noisier than others. Sometimes the room can be changed if it is really disturbing to a resident.

Coping with Loneliness, Loss, and Grief

Dealing with emotional pain and loss is a sad but inevitable aspect of life that all individuals, both in and out of nursing homes, must face. What do nursing home residents have to say about how they've coped with these matters, and what can be learned from their experiences?

When a resident feels lonely, he or she usually tries to get involved with something or someone:

Sometimes I do feel lonely, but I've got friends I go to. I'm a great reader. Sometimes, I sit here and think things over. How did I get here? Did I do the right thing? How is so-and-so making out?

I have lonely days, like most people. I long for old friends on the street. But sometimes I go to bingo or something.

Sometimes I feel lonely. I go off down the hall and it kind of wears off. . . talking to different ones on the way.

It's lonely in the afternoon for a couple of hours. . . then it gets better.

Residents, families, friends and staff are all affected by the losses accompanying death:

I figured she'd wake me up some morning and she'd find me asleep and just carry me away. I did hope that would happen in a way.

You get used to a place at the table at lunchtime, dinnertime. When they don't show up, you wonder what happened.

I think the hardest part is she doesn't want to live. She'll say, "I have lived long enough. I'm tired and I just want to go to sleep and not wake up."

Life-Prolonging Procedures

Issues of loss, illness, and the possibility of death are subjects which few people find easy to discuss. Yet, such issues deserve consideration by both residents and family members as they often involve decisions which will need to be made, such as what to do if certain life-prolonging procedures become necessary.

Here is what one relative said about a family dilemma:

The only problem I've got is what are we going to do if they put a tube down her? We all say there is no way we are going to allow it, but I don't know when it gets right down to it. Yes, the doctor knows how we feel about it right now, and says we'll face that when we get to it. It is a big decision and I spent a lot of time thinking about it. It is so unfair. They do not die with dignity.

This kind of decision does not have to be left to the family to decide. It should be decided by the resident and the family long before the problem is at hand. The decision is much easier if the resident's wishes are known. As one family member said:

There have been other cases in which the doctor has done what the living will would have done without the living will at hand. You rely fundamentally on your relationship with the physician.

And, according to another:

The guardian took me aside and said there are some decisions you are going to have to make. If he goes into heart failure, do you want them to call the paramedics and resuscitate? I talked to the nurse and the wonderful social worker. I said, "No, I didn't want him resuscitated. He is 87 years old. He has nothing to look forward to in his life but being a vegetable."

What can we learn from this?

- Find out what your state law says regarding living wills and durable powers of attorney for health care decisions.
- Talk together about the issue and decide what the individual really wants.
- Talk with your doctor and be sure you are in agreement on the issue. The doctor can tell you what the choices are.
- If no decision has been made by the time you enter the nursing home, ask the social worker, doctor, clergyman and/or someone with whom you are comfortable to sit down with you and discuss the issues.

At the Time of Death

One family member talked about the actual death of her stepfather. She lived far away and couldn't be there herself, but she was concerned; she wanted to be sure he was not alone or afraid at the time of death:

I wanted someone to be with him when he died. I had visions of him being frightened and alone. He died so quickly that I don't think he ever knew. He was sleeping most of the time the last time I was there... from what I saw there, he wasn't frightened. He just went to sleep and didn't wake up. A nurse had gone in to give him medicine and he died right there.

Who Should Be with the Resident at Death?

- The family, if they can cope with it. Nothing more need be done than to sit and hold the person's hand.
- If no family is available, then the closest friend is appropriate.
- Close friends in the nursing home should be involved. One of the nursing homes always involved the other residents, if they wanted to, at the bedside of the dying person. They said it made it easier on the residents after the death if they had a chance to be involved. Another home rightly notified a resident of a friend's impending death. When the friend went to visit, the social worker stayed in the room. They were unable to have private last words together.
- Staff not only care for the resident but often have developed relationships. They, too, may wish to say goodbye. It may seem odd to residents, families, and friends that staff are affected, but they are.

Opportunities for discussing impending death should be possible for staff, families, and friends.

Memorial Service

Many nursing homes have a memorial service for a resident who has died. If this is not done in your home, it is a good topic to be addressed by the Resident's Council.

The chapter "Getting What You Need in a Nursing Home" provides further discussion of the functions and activities of the Resident's Council.

STRUCTURE, SERVICES, AND STAFF

Structure of a Nursing Home

If you go into the home and look at the directory. . . it looks like the directory of the Department of State. It is a complicated place.

I did not realize how much there is to a nursing home beyond nursing care. This home has a very good range of activities, all of which are designed to restore and enrich the life of these people to the extent possible.

A nursing home offers more than simple nursing care. Homes employ a variety of staff to help meet the needs of residents. Even for those who have lived in homes for a while, the distinct responsibilities of various staff persons, such as nursing aides versus a charge nurse, may be unclear.

In addition, some homes differ in staff and services offered. For instance as noted earlier, not all offer physical or occupational therapy, nor do all of them have full-time social workers. This is an important point to consider when selecting a facility.

Services offered in a nursing home include medical, dietary, pharmacy, recreation, and social services, plus rehabilitation, occupational, physical, and speech therapy.

Staff persons responsible for providing these services include the following:

- Administrator
- Director of nursing
- Charge nurse
- Licensed practical nurse
- Nurse's aide
- Medical director
- Physician
- Social service director
- Dietary supervisor
- Patient activities coordinator
- Occupational therapist
- Physical therapist
- Maintenance and housekeeping staff
- Medical records supervisor.

There is a complete description of the scope of nursing home staff responsibilities in Appendix C.

It will be helpful to get to know the different staff persons and their assigned duties and responsibilities. You might be able to obtain a listing with the names of the various personnel in the home.

Personal and Therapeutic Care

You may wonder how staff and services are organized for the benefit of the resident. Who decides which services are necessary for each person? A family member describes the process very well:

. . . they have these interdepartment conferences. In theory and, in fact they are looking at each resident, each (discipline) from the standpoint of his own expertise. Out of that, they are trying to build a valid treatment for this resident. That takes a lot of time.

For each resident, a plan of care is devised to make the resident as independent as possible and to achieve the highest possible health status. For instance, a plan of care for a resident with severe arthritis might include the following:

- Medicine for pain ordered by the doctor
- Bathe self with assistance only in areas unable to reach
- Shower two times weekly
- Physical therapy three times a week
- Occupational therapy once a week

- Enter at least one activity of own choosing weekly for the next month
- Up in wheelchair for two hours, three times a day
- Teach resident to assist in transfer from bed to chair within a month's time
- Assign a volunteer (preferably German speaking since her first language is German)
- Eat in dining room at noon. Assist to open milk carton.

In this case, bathing and transferring herself is part of her therapy. This resident still had some use of her arms. To maintain her strength and mobility, she must continue to use them even if she does it more awkwardly and more slowly. Physical therapy and occupational therapy are ordered by the physician for the same reason.

The family of an Alzheimer's victim says:

They want them to dress themselves as long as possible. Jim didn't do it very well. He would come in with his pajamas and two or three shirts on. That part was good.

Here are some points to remember about the care plan and how family, friends, and residents can become involved in the planning process:

- Find out who is responsible for developing the care plan and tell the individual you want to be involved in the plan's formation. Both the resident and family (friend) should be involved in the process. If the resident is unable to comprehend, then the family or designee should represent him/her.

They have patient care conferences once a week. When my brother comes in June, if the family wants to meet with them, I'll let them know and they'll schedule it. They will have Mother there, the doctor, anyone you want. Oh, yes, lots of families take advantage of it.

- If it is not the policy of the home to include the resident and family, request a meeting to discuss the plan after it is complete.
- Care plans are evaluated every month or more often if needed. The resident should also be included in the re-evaluation and be aware of the changes that are constantly being made in the routine.

One family member reports on how he felt about the care planning process:

So we came up with this idea, that by giving her hot cereal with a lot of milk in it, she can drink it. We worked it out with the staff. They don't do anything without checking with me first, to ask me if they can do it. At the time I thought it was a lot of responsibility on me, but the more I thought of it . . . I mean if I had walked in there and seen that without them talking with me that probably wouldn't have gone over very good.

Food Services

It is important to visit a nursing home at mealtime whether you're planning to enter or a loved one has done so already. Mealtime is one of the most important events of the day in a nursing home and is eagerly awaited by the residents. Good food, attractively prepared, is important socially as well as nutritionally. Residents, families, and friends have offered these observations about the food services:

The food situation is as good as any institution. You have a choice on the menu.

The most important thing next to sleep is the food service.

They should have better food for the price we pay—too much canned stuff. They sent me up an apple. I can't eat apples because [I] have no teeth.

The meals have gotten better. They make them so that it has a top on it so it will stay hot. Before, some of them wouldn't eat it because it was cold.

One day the diet supervisor and the tray came up at the same time. I said, "Check the meal." There were five things missing. So the dietitian goes downstairs and gets it herself.

When visiting at mealtime, points you might raise include:

- Is food appetizing and nutritionally well balanced?
- Do the meals served correspond with the menu for that day?
- Are between-meal snacks available?
- Are special needs such as low sodium, diabetic, kosher, or "soft foods only" accommodated?
- If residents do not like or eat what is being served, is there an alternative selection?
- Can residents eat in their rooms?

How might you deal with complaints about the food? You may talk to the dietitian or food service director about the problem. Ask for suggestions. Or you could ask for the doctor's order when a particular food is required.

Families and friends occasionally should be present at mealtimes to see what is on the tray and whether the resident is able to eat it. If weight loss is suspected, ask the head nurse what the last two weights have been. All nursing home residents are weighed every month. If there is a weight loss, find out how that will be handled in the plan of care. Check to see that changes are instituted and carried out. Do not leave it to chance. Bring in treats from home for a change once in a while. Check with the head nurse to be sure that what you are bringing is acceptable.

Dining Room Seating

Eating in the dining room is a social occasion and residents should have a choice as to where they sit and with whom they sit. What should you do if there is a problem?

- Talk to whomever is in charge of dining room seating. Ask if there is a way you could work out a better seating arrangement together.
- If that doesn't work, go to the nursing director to discuss the issue. This is a quality of life issue and is very important. As with other important concerns, you must press for your rights.
- If the policy is to have a mandatory seating arrangement, then the issue should be addressed at the Residents' Council immediately.

Activities/Programs

Each nursing home has a monthly calendar of group or individual activities that is usually distributed to each resident and centrally posted. Activities should also be available at the bedside for those residents with limited ability. Besides being enjoyable, these activities are good therapy. Many residents enjoy the activities as survey respondents indicate:

We have a garden group, current events, music and bingo. We have a men's group, a women's group. We have speakers. . .we are having one on Monday about the personal needs allowance.

I love the exercises. We get 'em every Thursday and Friday. Oh, they are wonderful!

In addition, many enjoyable activities can be continued after entering the nursing home. Interest in reading, writing, listening to music on the radio, knitting, watching favorite TV programs, and socializing doesn't diminish:

I have a radio in my room. Turn it on first thing in the morning. Like to know what is going on.

Saturdays we have nothing to do and we just love that. You take your time getting up. You lay back down after breakfast. . .

I read the papers, you know.

I made these carvings here. . . I use grinders. . . I have my own tools. My niece is bringing them to me.

Many residents spoke of the need to feel useful, productive, to find a way to be helpful in the nursing home with a purpose in life.

At ten, I do some announcements out there on the loudspeaker. Activities. . . I announce the weather reports, sports, all the games. I was a dispatcher for the highway department before.

A nurse in the other unit came and asked me to visit somebody over there. I did, and the woman is older than I am. She is very shy and she just likes having someone say hello to her.

When researching nursing homes, check to see if they can accommodate particular interests. Once admitted to a home, advocate for desired activities and programs. Residents, families, and friends must work with the activities director in providing meaningful programs. The activities director cannot know what you would like to do if you don't let him or her know your interests. Remember:

- You don't have to participate in activities if you don't find them to your liking.
- Work through the Residents' Council to be sure activities are available for all age groups represented in the home.
- Let the activities director know when you have an idea either for your own activities or for a group activity.
- If you have an idea for a group activity, ask other residents if they will join you in making a request, first to the activities director, and, if necessary, through the Residents' Council.

- Nursing homes do not allow residents to work for reasons of safety and to avoid the appearance of exploitation. However, there are often times when a small job can be assigned which would not be considered inappropriate. AARP's survey found these examples of small jobs done by interested residents:

I take care of the birds and the plants in the home.

I change the daily calendar.

Laundry Services

The survey found several kinds of laundry concerns. Ruined and lost clothes, and the cost some nursing homes assess to do personal laundry, topped the list of complaints. Ruined clothes can be prevented by bringing the right type of clothing to the nursing home, alerting staff to special care needs, or having a relative or friend take home laundry. If the commercial laundry at the home is going to take care of a resident's clothes, then items that can weather that type of harsh treatment must be brought. Some homes separate personal laundry from sheets during laundering, but even then the clothes must be sturdy cotton or synthetic. Clothes that have to be dry-cleaned are appropriate only if the family is going to take care of the dry-cleaning and if the resident is continent.

Clothing is lost when it is not properly marked or if there is a poor system for sorting and delivery to the room. Theft of personal possessions is also an unfortunate occurrence. Here are some typical comments:

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She is always losing clothes at the laundry. . .She had a little afghan that disappeared almost as soon as she got there. Do you know—it came back almost a year later?

A laundress in a nursing home says:

They are not lost in the laundry. They are lost in the delivery. They are short-handed. You start putting clothes away, a resident needs attention, you lay it down and pick it up and forget which room it goes to. It goes somewhere else. We also have people who will walk in and they'll see something that looks nice and they will wear it for a while. If it is marked, sooner or later it gets where it belongs.

The Residents' Council may be able to help in this situation. It might suggest that:

- You work with the laundry department and the administration to work out a system of delivery
- The nursing home assign the same person to delivery each time.

Relating to the Staff

You will find that some staff are going to be more to your liking than others. Here is a sample of comments:

There is a tendency among even the best nursing staff to treat elderly people in a fairly preemptory way. They really can't stop and treat Mrs. So-and-so as if she were their own mother. They have got to go on and get their routine accomplished.

. . .and the work is tedious and she takes abuse from residents and families when they don't feel good.

The supervisory nurses are so busy that they cannot properly teach the assistants when they need it. Usually, these people get very little training.

Some of them are bad. Those are the ones you just sidestep. In a way, it's a game with me.

There is one assistant I have fought with for a long time. She says I am spoiled and that I think I'm special. I tell her I am special. She has such low self-esteem that she can't deal with that. She is on vacation now and yesterday I got a card from her with the printed message "You're Someone Special." So it must have made some impression.

Each one of the staff has a different way of doing things. No person is the same. I expect consistency but can't get it.

Not all nurses do everything well; they, too, are human. It is difficult for the resident who needs a stable environment to cope with this. On the other hand, variety can enhance the social aspects of living in a nursing home. Two residents offered these observations:

Everybody can't be served at one time. Some are willing to wait their turn, others are not.

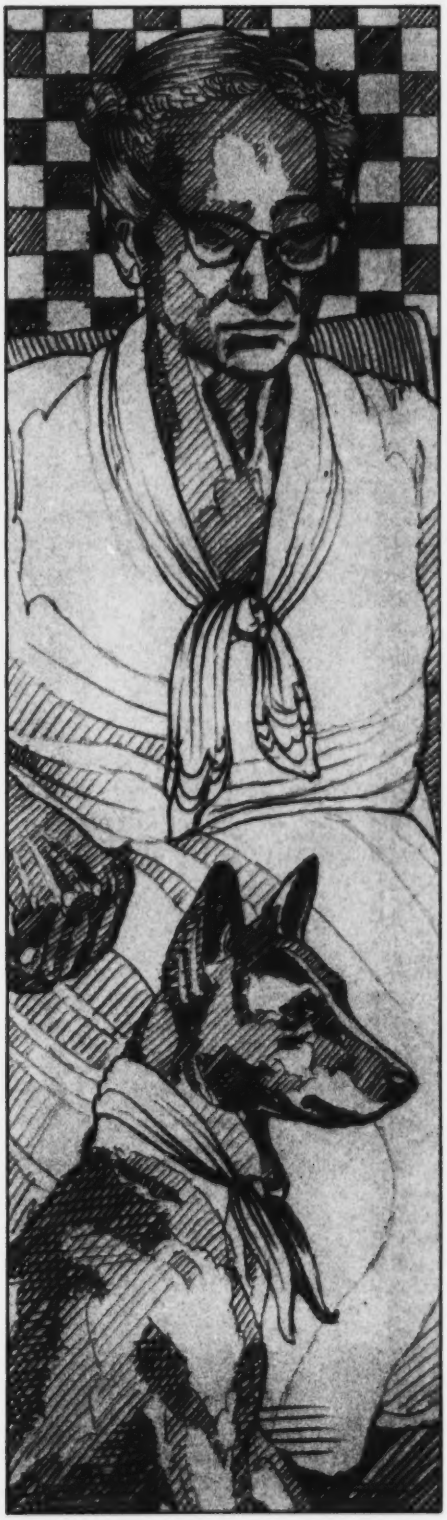
Some are sicker than others. They have to be attended first. That is understandable. Sometimes you get burned up when the staff uses the time for gabbing.

There are two issues here. One concerns the organization of the day's work. The other concerns adequate supervision of the nursing assistants by the nurse in charge of the unit. The resident does not have a right to dictate who will be taken care of first, but he or she does have a right to know, on any give day, when care will be provided, and by whom, and assured that immediate care will be provided if needed. The head nurse should see that this happens and should be spoken to if it doesn't.

Keep in mind that emergencies do happen and they do require changes in plans. If the charge nurse does not appear to be able to supervise the nursing assistants after you have brought it to his or her attention, be sure to talk to the director of nurses about the problem. If enough people do it, change will more than likely occur:

I complained. Matter of fact, I think I helped get rid of one of them. I didn't do it alone but I helped to.

GETTING WHAT YOU NEED IN A NURSING HOME



Emotions and reactions don't change once a person enters a nursing home. Annoying or upsetting things will still happen. How do residents cope? Sometimes they talk to the director of nursing if there is a staff problem, or they talk about it with family and friends:

I would take it down to the office and tell the boss (director of nursing) that I had something on my mind that was bothering me. Just recently, the head nurse. . . had an attitude towards me. I wanted to know. It hurt my feelings. She didn't mean to slight me—they had been pretty busy talking in the office—that's why. There was nothing wrong—I believe her.

I talked it over with my own people.

Others report on how they deal with a problem:

I have learned to take things one day at a time and not to worry about things I can't do anything about. That's the one thing I can't say I particularly did before moving here.

We have a Resident Council meeting once a month where we give complaints. It's helpful 'cause it brings things to the fore—things you can't do anything about but they can.

Begin getting what you need by knowing your nursing home rights and working with your resident and family council. As mentioned earlier, nursing home residents are guaranteed certain specific rights, known as the patient's or the resident's bill of rights. Refer to the earlier section of this Guide for further discussion and identification of these rights. Most nursing homes have resident and family councils. Such councils provide an opportunity for residents and family members to meet together, usually once a month, and voice their concerns or thoughts about the facility or the care being provided, and suggest ideas for future activities or changes they feel are needed.

Often a staff person, such as the activities director, will facilitate the meetings, though the councils should be permitted to hold a meeting without staff present. Key staff persons might be invited to attend and specific issues and problems can be discussed openly so that a solution might be worked out. Other times, councils can take part in planning activities, menus, and social events. The effectiveness of a council largely depends on active involvement of its members and a strong facilitator, and the support of the administrator.

Ombudsman

An ombudsman is an advocate who is responsible for investigating and resolving complaints made by, or on behalf of, nursing home residents. Ombudsmen also monitor the development and implementation of laws, regulations, and policies affecting nursing homes. The Older Americans' Act requires that each state have one full-time state ombudsman. In addition, many cities and counties throughout the country have a local ombudsman available to respond to complaints in their areas. A listing of state ombudsmen is in the Appendix E of this publication. Your state ombudsman can refer you to a local ombudsman, if your area has one. Often, there are volunteers working with the ombudsman's office, who regularly visit nursing homes and respond to complaints.

State Licensing and Certification Office

This office is responsible for regularly inspecting nursing homes to ensure that mandated standards are met. Nursing homes must meet many specific standards to be certified or licensed, and thereby operate legally. The office in charge of state licensing and certification, generally is housed in the state health department. A listing of these state offices is in the Appendix E.

Problem-Solving Steps

If a problem arises, there are a number of steps a resident can take. Begin with the easiest and the least confrontational steps. If the problem persists, additional steps may be necessary.

Start by discussing your concerns directly with one of the staff persons involved. If you do not get satisfaction from the staff person, approach the supervisor. The following lists the order in which individuals should be contacted if a problem persists:

- Head nurse on unit, who may be called the charge nurse
- Director of nursing
- Nursing home administrator
- Resident and family council
- Ombudsman's office
- State licensing and certification office.

Try to be objective in gathering your facts.

- Be firm in your approach but with an attitude of "we can solve this thing together." Be assertive but try not to put anyone on the defensive. No one likes to be accused of anything.
- If you are able, keep notes on the conversation. Then, if something is agreed to, you have notes to refer to should no action be forthcoming.
- Try to solve the problem in-house before going outside.
- Check with other family members, friends, and the residents if you have reason to believe the problem is widespread. Concerted action brings results sometimes.
- Ask for information about why it happens the way it does, what options for change are available, and what it would take to do it the way you want.

What is the experience with these systems for correcting problems? Residents reported these solutions to problems they experienced:

Do not be afraid to be assertive of what you want. The same goes for families. They are paying the bill. I think it's like any other group, you have to watch out for your rights as a consumer. If the staff won't answer the call bell, you just use the telephone. If I have trouble with the medicine nurse, I pick up the phone and tell the supervisor. The response depends on who is on duty.

If the family sees something wrong, they report it to the nurse. Like Mr. Applebaum, when his daughter finds something wrong, she reports to the charge nurse. They do get action every time.

Families reported:

The head nurse is gone. I think we may have had something to do with a couple of them being removed. They have a new head nurse and things have started to change since she came on. Now they have a helper nurse when she is not there. They are very helpful and quick when we need them.

I was pleased that at least the administrator was roaming around there. First time I've ever seen him.

Well, I really did make a fuss. I went to the doctor and he went to the nurses. When the nurses realized I knew how they didn't take care of my father, they began to turn him more often.

It is very wise to get in touch with the ombudsman's office. They have a large amount of control over nursing homes. Our ombudsman has been very helpful. We went on Saturday and Mom had a bruise on her chin. The ombudsman happened to be there, too. She went right away to find out what happened.

I was interested in learning from the state office of Regulatory Affairs that they have had a number of complaints from families—complaints of low staffing, odors.

When the Reaction Is Defensive

In response to your concerns or complaints, the nursing home may become very defensive and use tactics that can be disconcerting unless you are forewarned. For instance, one family member reported this experience:

We had a meeting with the Administrator. They said we decided to have the staff here since you seem to get so upset over very minor things. I walked into the room and they had twelve people. Every time I opened my mouth, they had a reason why I was expecting too much. They said the aides just didn't have the proper background and education.

What can you do?

Whenever you ask for a meeting you can always ask the meeting organizer who will be there. If he or she suddenly changes the ground rules and adds people, say politely that this is not the meeting you agreed to. Tell the meeting organizer you would like to talk in private and suggest that you could call in the others if the subject concerns them. If that is not agreeable, you have a perfect right to terminate the meeting and go to the next level of the hierarchy for help. You can be perfectly open in what you intend to do.

You may encounter staff members who tend to minimize a problem brought to their attention. One family member who was interviewed, knew that her mother did not bruise easily. She rightly gave some history to support her theory that her mother had been abused by a staff member and continued to pursue the matter:

. . . bruises on the face. I don't believe so. That has to be purposefully done. . . just one side of the face. As I said they were on the neck and chest. The head nurse tried to tell us that as we get older, the capillaries break. . . those are bruises . . . that was pretty ridiculous. I said, "I have known her for 30 years and I have never known or seen her bruised like that except when she fell down the steps," and it really wasn't that bad as she was here.

The advice here is, if you have reason to believe they are wrong, continue with your attempt to right the wrongdoing. Another person tried talking long-distance with a nursing home staff member:

It was doubletalk. You try to have communication with them and you think you know what they are saying. You hang up and say, ". . . did they say they would or didn't they?" I can't prove what Mother is saying. They say, "Are you sure your mother is telling the truth?" One time they asked me if I wasn't just feeling guilty. It's a tactic that is going around.

This person lived far away from her mother. After telephoning about the problem, she probably should have followed up her complaint with a letter. She also should ask for a written reply. Then, if she has to take additional steps, she has a complete set of correspondence.

If you live far away from your loved one, remember—there is an ombudsman in every state and often local ombudsmen are assigned to communities. Even if you do not live in the area, you can phone the appropriate one and request assistance with such matters. A state ombudsman listing appears in Appendix E.

Fear of Retaliation

Many residents and family members will not defend themselves when their rights have been violated because they fear retaliation from staff if they complain. This is a valid and understandable fear. While any form of retaliation by staff, either blatant or subtle, is illegal, it does happen on occasion. Do not let fear stop you from defending your rights. Living in fear of being mistreated, receiving poor care, or tolerating neglect or harassment is an insupportable and unacceptable situation for anyone, especially one who may be suffering from an impairment or affliction which necessitates nursing home placement. A nursing home resident offered this advice:

Understanding resident rights and standing up for them will make you feel you are in control of your life. Do not worry about how other people will respond. How others respond does not change the fact that you are in control of yourself.

Talk with other residents and family members. If others have the same or similar problems, that means you are not the only one. The resident or family council along with the administrator and appropriate staff (such as director of nursing) should help resolve the problems for all of you.

It is important to note that administrators and directors of nursing are not able to know all that goes on in the facility *all* of the time. If there is a problem, for instance, with a particular staff person, or a problem experienced by others in the home, such as meals not being served at proper temperatures, often they will be grateful for your bringing it to their attention.

If it becomes necessary to contact your ombudsman for assistance you should know that he or she is required to investigate and resolve complaints and is not permitted to reveal the identity of the resident or family members making the complaint, unless their permission is given to do so. There may be, however, some complaints which the ombudsman cannot fully resolve unless the identity of the person is revealed.

Remember, there are people who are willing and able to help ensure that your rights are not violated but to obtain their assistance you must take the first step and report the problem. If you persistently stand up for your rights, you may prevail.

When Nothing Works

I think you wear down from this type of thing. They can wear you down. If you aren't making any headway, you finally know you have to take the resident out of there.

When all else has failed and the situation remains intolerable, you may want to consider moving to a different facility. This is often easier for those who are not yet on Medicaid. As previously mentioned, private-paying residents are usually more desired by facilities since they often pay for care at a higher rate than do Medicaid residents.

For assistance in locating and admitting a person to a different facility, you might speak with the social worker at the nursing home, contact your Area Agency on Aging and/or speak with your local ombudsman for suggestions.

Summary of What Can Be Learned

As you have read, there are a variety of issues and concerns that residents and their family members have faced. In summary, what can be learned about approaches to cope with some of these concerns and issues?

- Many things that may cause conflicts are addressed by the resident's bill of rights, and you have a right to raise these concerns.
- Little things that annoy you loom large if they are not addressed. Be polite in making requests and work together with staff to solve problems.
- When making a complaint, gather your facts and observations and be firm but patient. For instance, you can say, "This is what we are observing and experiencing. Is there some way we can help to improve it?" With this approach, the staff isn't tempted to be defensive.
- Residents, families and friends should involve themselves in resolving day-to-day annoyances.
- Talk to other residents, families, and friends and decide if others are noticing similar problems. If so, bring it up at the Residents' or Family Council to address.
- If there isn't a Family or Residents' Council, start one. If no council exists, a group of residents or family members can always request a meeting with the administrator or appropriate staff person(s).
- Work through the Residents' Council to support, encourage and recognize the efforts and contributions of the staff. They will be forever grateful.

If, despite your efforts, improvements are not made or if trends in poor care persist, contact your ombudsman for assistance.

ISSUES OF POOR CARE OR ABUSE

Unfortunately, instances of poor care or abuse in nursing homes continue to exist. Efforts to monitor nursing homes have been expanded, nevertheless, it is important to know what to do should one encounter such a situation. This section covers some common complaints.

Unanswered Call Bells

Well-supervised nursing assistants answer call bells immediately. For many residents it is their only lifeline for help. Let's hear what it feels like to be dependent on having someone answer a call bell:

There is nothing worse than lying down and feeling like you are trapped. This motorized wheelchair didn't work for two days. I was at their mercy and it was terrible.

If this is a problem for you or your loved one, make sure to let the director of nursing know.

Improper Use of Restraints

Restraints may be used to protect residents from harmful actions to themselves or others. The physician must order them and state the specific use and duration of use. Sometimes restraints are called protective devices. Restraints should not be used as a means of controlling residents due to an insufficient number of staff available in the home to provide care, but rather they should be used to benefit the resident.

Restraints are divided into two categories: physical and chemical. Physical restraints prevent the resident from moving around freely. The most common physical restraints are:

- **Gerichair** with an attached tray. Residents cannot move the chairs themselves nor can they get out of them.
- **Vests** or **waist restraints,** which are used in a chair to prevent the person from walking, or in a bed to prevent the resident from climbing over the bedrails and falling.
- **Bedrails** prevent the resident from getting out of bed. Essentially, they make the bed into a crib.
- **Wrist restraints,** used to prevent residents form turning onto or pulling at a catheter or naso-gastric tube.

Chemical restraints control the behavior through ingestion or injection of prescribed medication. A family member reports on what she saw as unnecessary drugging of her mother:

They had her on Haldol. We'd see her and she'd be asleep. We would say, "Mother," and she wouldn't respond. I said they were giving her too much. I don't want to see her that way. It wasn't doing her any good. It was easing their problem... getting her out of the way. We would go in there and she couldn't eat. She was just out of it.

If the resident is hard to arouse or is acting much differently than usual, go to the head nurse to find out what is going on. Think carefully about what she tells you. Do not accept platitudes. Ask about the resident's medicines and find out why each one is prescribed and the expected side effects.

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If you don't want excessive chemical restraints used, put it in writing. Be sure the physician is notified and the order for medicine changed. Ask the next day to be sure. Call the doctor yourself if the staff will not do so. The resident should be more easily aroused within 24 to 36 hours.

To summarize, it is a resident's right to be free from chemical and physical restraints except as authorized in writing by the physician for a specified and limited period of time, when necessary to protect the patient from injury to himself or others. It is frightening to be restrained. If restraint is truly necessary, sit down with the doctor and work out an acceptable agreement on what is necessary. Do not let a physician dictate to you but rather, work towards the least possible restraint.

Residents who are confined to bed and cannot move themselves must be turned at least every two hours to prevent bedsores. Relatives and friends must be watchdogs to see that this is done.

Here are a few practical actions to lessen the use of restraints:

- Use a very low bed, so that if the resident falls he or she will not hurt themself as much. Bedrails are often unnecessary.
- Residents who get up in the night are usually trying to get to the bathroom; therefore, request that he or she be toileted during the night.
- Go over the care plan with the nurse to make sure that exercise is scheduled regularly. Then follow up by being there yourself to make sure it happens.
- If the residents take walks during the day, they are usually calmer and can be without restraints as long as the aides will toilet them regularly.

Not Toileted Regularly

Older people often have to go to the bathroom more frequently than younger people. Some have to be toileted every two hours. The following are examples of poor care that can lead to bedsores and/or urinary tract infections:

Daisy kept saying she had to go to the bathroom. We went to the nurses. . . they said the people on the east side of the building go to the bathroom at three o'clock. This was not Daisy's time to go to the bathroom. We went storming to the Director of Nurses and she took her.

They say they can't take her to the bathroom whenever she needs to go. So they either clean her up after she goes or they put on a diaper.

What Can the Family or Friends Do?

A nursing home should not have permanent bad odors. There are unpleasant smells once in a while, especially after meals, but constant odors should alert you that care is poor.

Family and relatives must take responsibility for making sure that the resident is kept properly clean. Here is how to check for cleanliness:

- Overall appearance should be clean
- Mouth looks clean and fresh—no odor
- Men are shaved
- Hair is neatly combed
- Fingernails are clean, no feces in them
- Eyeglasses are clean
- No body odor
- Regularly check buttocks and between the legs for filth. Simply find a way to gracefully do it; i.e., "I'd love to rub your back. Wouldn't that feel good?" "I'd like to accompany him to the bathroom."
- If the person is confined to bed simply pull back the bedclothes, exposing one part at a time and look. Check to see that the skin is clean and the bed is not wet. Use the chain of command to be sure the individualized plan of care includes a toileting schedule which is followed. Come in at a different time of the day and see that he/she is toileted.

Dehydration

Dehydration occurs when one is not getting enough fluids. Nursing homes are required to provide a clean pitcher of cold water at the bedside of every resident. Several things can go wrong: the fluid is not provided or the resident cannot or does not drink it or needs assistance to do so. If an older person does not receive enough fluids (about ten glasses a day in all, including coffee, etc.), dehydration can result. Infection, confusion and/or bedsores also can result from dehydration.

Look for a fresh pitcher of water at the bedside. If the resident cannot reach it, someone should offer water when medicine is given or between meals. If the weather is hot, water should be offered every few hours. At mealtimes, the assistant should check to see that the liquids on the tray have been consumed. Families and friends can check that, too. Symptoms that should make you suspicious of dehydration include; very dry mouth, very dry skin, eyeballs look sunken, heavy speech, unexplained confusion, and/or unexplained drowsiness.

Poor Nutrition

Poor nutrition usually occurs when a resident needs help with but isn't given assistance with feeding or if the food is unappealing.

Observe during mealtimes; see if other residents who can't feed themselves are being fed. Try to visit at dinner and on weekends, since that is when there may be fewer staff. Look at the trays going back to the kitchen after a meal. Have they been touched or not? Just because the staff say an activity such as eating was written on a resident's chart, doesn't always mean it actually occurred.

Bedsores or Decubitus

Decubitus, otherwise known as bedsores, are open sores on the skin which occur because of a combination of lack of movement, lack of cleanliness, lack of fluid, and improper nutrition. They can lead to infection and death. Bedsores are preventable.

What can be done to prevent them?

- Be sure there is adequate food and fluid, that the resident is clean and dry, and is moved every two hours, or more if necessary, with assistance if unable to do so alone.
- Check your relative's or friend's skin every time you visit.

I check her all over every time we visit. I rub her skin with lotion and that way I can look at every part of her body.

- If you see bedsores, have the nurse provide treatment immediately so that they heal and do not become worse.

Look for:

- Reddened areas that do not disappear, especially over buttocks, ankles, and heels
- Broken skin in any of the same areas
- Gauze and tape covering something in the same areas or
- Any other kind of covering in the same areas.

Contractures

Contractures occur when a muscle contracts or shortens from disease. It is prevented by moving all parts of the body every day. Be sure that the care plan includes range of motion exercises if your relative is unable to move any part of the body by himself.

Abuse

Abuse can be physical or mental. Both are a criminal violation of the law and are also prohibited under the resident's bill of rights. Whenever a dependent population is being cared for by others, the potential exists. Sometimes it occurs because of the stress of the job. Stress is usually caused by:

- Inadequate training of staff—they simply do not know how to handle their jobs
- Inadequate supervision of the staff
- Staff shortages and
- Personal reasons.

In addition, it may not be the staff who is responsible for the abusive treatment, but rather, an outsider who is visiting. Here are some examples of mistreatment as told by relatives and friends of residents:

It was dried blood in the left nostril, corner of the eye, and nose scratched and red, left side of chin bruised, left cheek scratched. Blood just under the skin bruised along collar bone and left shoulder to center, left hand badly bruised.

One night I went to visit and there was a sleet storm. . . and I had to spend the night in the empty bed in Mother's room. First they scolded her, using obscene language, for wetting the bed. Then, they told her snakes were around her feet and she better move them. Mother is unable to move them. I spoke to the Director of Nurses, but nothing happened. I went early one morning and spoke to the aides myself. Mother did not complain about them anymore.

"If you don't eat we are going to put that tube down you again." I looked at her and said, "What are you talking about?" The nurse said, "We've been trying to teach her a lesson. We force feed her." She said, "It was really hard, because she is a strong lady and it took five of us to hold her down." The Administrator turned me over to the Director of Nurses who gave me all these platitudes that these are normal procedures with elderly people who become obstinate. They have a standing order from the doctor. That head nurse wasn't there much longer.

One resident, when asked what advice she would offer for a publication on nursing homes said:

Tell it like it is. Don't be too sweet about it. There is a lot of covering up about treatment of residents.

Her advice was followed because there are things that can be done to prevent abuse.

Neglect: Follow Your Hunch If You Think Something Is Wrong

Sometimes staff in a nursing home do not notice a change in the condition of a resident. Or, they do not assess the resident's abilities and automatically attribute any changes to dementia. If you think something is amiss, persist until you are satisfied with the answer. Here are some examples from families and friends of residents:

Jennifer kept complaining that she had a pain in her foot. This young nurse came in and I told her I was concerned and wished to have the foot checked. She told me to stop interfering with medical care or I would be prohibited from visiting. [Illegal since that is the resident's right.] I said, "I want you to call the doctor or I will." The doctor ordered an X-ray and there was a slight fracture.

Frances said her tummy hurt. I felt it and it was hard as a rock. I told the nurse and she said that this happens to old ladies after they have had hip surgery. So I called the doctor. She came and it turned out that Frances had a very serious bladder infection.

These visitors challenged staff answers and rightly so. Even though a staff member may have more medical knowledge than you, your hunch may often be correct.

Summary

If you want to get the most for your family member out of a nursing home, it is up to you to know all you can about the nursing home.

Although this booklet describes several unpleasant issues and recollections of residents and family members, remember that many good things were said about life in a nursing home; friendships developed, and for many, their quality of life improved after their move there:

Moving here changed me because it made me stronger and I know my own self. Living according to institutional rules doesn't mean I have to compromise myself as a person. I've gained independence, wrote a book.

I think I've gotten stronger. I'm not sad to be here, I'm relieved.

They take excellent care of the residents. Mother is healthier and in better shape now than she was when she was admitted [two years ago].

I learned to dress and undress myself since coming here... things I never would have thought possible.

They take such wonderful care, they have given her years of life. She always says, "They take such wonderful care of me."

While nursing homes are often the last choice for many, they need not be looked upon with fear and dread. Nursing homes can and do maintain the safety, health, and well-being of the residents.

Being mindful of the rights that protect residents and aware of the avenues available to seek changes or improvements in situations which may arise will help you make a nursing home environment even better. One resident advised:

Listen to them. Don't discount what they say. Never take a complaint lightly. If there is a complaint, there is a wound somewhere. Help the residents maintain dignity in personhood by allowing them to keep old habits and wear good clothes.

Knowing about nursing home responsibilities, the rights of residents, and related issues covered in this publication, will enable you to make informed decisions about your life and the lives of your loved ones. By being informed about such matters, you will be more in control of your life. If a problem does develop remember: you are not alone. There are people who can help you. When change and improvements are needed; advocate for them, the more we advocate, the better for all concerned.

APPENDICES

A. Checklist for Selecting a Nursing Home

B. Nursing Home Residents' Bill of Rights

C. Nursing Home Staff

D. National Association of State Units on Aging

E. State Long-Term Care Ombudsman Offices

F. State Agencies on Licensing and Certification

G. Selected Resources

APPENDIX A

CHECKLIST FOR SELECTING A NURSING HOME

This **CHECKLIST** may serve as a guide when looking for a nursing home or evaluating one in which you reside.

General

Ask to see the latest inspection report which describes problems identified and plans for correction.

How long have the current owner, administrator and director of nursing been with the facility? Has there been stability at these levels?

Is there a written statement of the resident's rights clearly posted?

Are visiting hours convenient for residents and visitors?

Location

Is the home near family and friends?

Is the home reasonably close to a hospital offering emergency services?

Does the location enable family, friends and the resident's physician to visit?

General Physical Characteristics

Is the nursing home clean, orderly, and relatively odor-free?

Is the home well lighted?

Are the rooms kept at a comfortable temperature and well ventilated?

Are toilet and bathing facilities accessible to handicapped residents?

Is the furniture attractive, comfortable, safe, and easy for elderly people to get in and out of?

NOTES

Attitudes and Atmosphere

Is the general atmosphere of the nursing home warm, pleasant, and cheerful?

Is the administrator courteous and helpful?

Are staff members cheerful, courteous, and enthusiastic or do they appear angry and intimidating?

Do staff members take time to visit with residents?

Do staff members show residents genuine interest and affection?

Are residents treated with dignity and respect by staff?

Do residents look well cared for and generally content?

Can residents bring any of their own furniture with them?

Are residents allowed to wear their own clothes, decorate their rooms, and keep a few prized possessions in their rooms?

Do staff knock on the door before entering a resident's room?

Do staff speak to residents about their activities and where the residents are being taken?

Do you see groups of nursing assistants watching television in anyone's room or in the day room or do they seem attentive to residents' needs?

Do residents, other visitors, and volunteers speak favorably about the home?

Is there a sense of fellowship among the residents?

Safety

Is the nursing home free of obvious risks, such as obstacles to residents, hazards underfoot, unsteady chairs?

NOTES

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Are there grab bars in the toilet and bathing facilities and handrails on both sides of the hallways?

Are hallways wide enough to permit wheelchairs to pass each other easily?

Do bathtubs and showers have non-slip surfaces?

What is the smoking policy in the facility? Does the policy consider both residents' rights and residents' safety?

Are smoke detectors, the automatic sprinkler system, and automatic emergency lighting in good operating order?

How would the facility handle an emergency evacuation?

How does the facility monitor the whereabouts of confused residents who may tend to wander?

Is there outside space that is secure for both confused and non-confused residents?

Are doors to stairways kept closed?

Medical, Dental, and Other Services

Is the prospective resident's physician willing to visit the home?

In the case of medical emergencies, is a physician available at all times, either on staff or on call?

Does the home have arrangements with a nearby hospital for quick transfer of nursing home residents in an emergency?

Does the home allow the resident to be treated by a physician of his or her own choice?

Is the resident involved in developing the care plan?

Is confidentiality of medical records assured?

NOTES

Does the home have an arrangement with an outside dental service to provide residents with dental care when necessary?

What is the staff to resident ratio for routine care and in case of an emergency evacuation?

How many residents are routinely restrained? How often are they checked and released? (They should be checked every 30 minutes and released and exercised for range of motion every 2 hours.)

For skilled nursing facilities:

Is at least one registered nurse (RN) or licensed practical nurse (LPN) on duty day and night?

Is an RN on duty during the day seven days a week?

Does an RN serve as director of nursing services?

(Effective October 1, 1990, these requirements will apply to all nursing homes)

If the person to be placed requires special services, such as rehabilitation therapy or a therapeutic diet, does the home provide them?

Pharmaceutical Services

Who is the pharmacist who supplies the facility and who conducts the quality control review?

How does the facility ensure residents' right to free choice of a pharmacist?

Food Services

Is the kitchen clean and reasonably tidy? Is food needing refrigeration not left standing out on counters? Is waste properly disposed of? Do kitchen staff follow good standards of food handling?

NOTES

Are nutritious between-meal and bedtime snacks available?

Are residents given enough food? Does the food look appetizing?

Sample a meal. Is the food tasty and served at the proper temperature?

Are special meals prepared for patients on therapeutic diets?

Are meals planned by a trained dietitian?

How does the facility arrange to provide substitutes or choices to residents?

Is the dining room attractive and comfortable?

Are small tables used rather than mess-hall type tables?

Do residents who need it get help in eating, whether in the dining room or in their own rooms?

Social Services and Resident Activities

Is there a trained, qualified social worker on staff? What services are offered (e.g. counseling)?

Does the nursing home have a varied program of recreational, cultural, and intellectual activities for residents?

Are there group and individual activities?

What training and qualifications does the activities coordinator have?

Is suitable space available for resident activities? Are tools and supplies provided?

Are activities offered for residents who are relatively inactive or confined to their rooms?

Look at the activities schedule. Are activities provided each day? Are some activities scheduled in the evenings and weekends? Are those posted activities actually taking place?

NOTES

Are residents encouraged but not forced to participate in activities?

Do residents have an opportunity to attend religious services and talk with clergymen both in and outside the home?

Do staff assist the residents in getting from their rooms to activities?

Are residents encouraged to participate in community activities outside the nursing home (health permitting)?

Residents' Rooms

Does each room open onto a hallway?

Does each room have a window to the outside?

Does each resident have a reading light, a comfortable chair, and a closet and drawers for personal belongings?

Is fresh drinking water within reach?

Is there a curtain or screen available to provide privacy for each bed whenever necessary?

Do bathing and toilet facilities have adequate privacy?

Does the resident have any input into the assignment of roommates?

Are nurse and emergency call buttons located at each resident's bed, toilet, and bathing facility?

Is there a lounge where residents can chat, read, play games, watch television, or just relax away from their rooms?

Is a public telephone accessible for residents' use?

Does the nursing home have an outdoor area where residents can get fresh air and sunshine?

NOTES

Transportation

Does the nursing home provide transportation for residents for recreational as well as medical purposes?

Is the home on a bus route for convenience of residents and visitors?

Financial Considerations

Is the home certified to participate in the Medicare and/or Medicaid programs?

Are many of the services needed included in the basic charge? What is not included?

Do the estimated monthly costs (including extra charges) compare favorably with the costs of other homes?

Is a refund made for unused days paid for in advance?

Is a list of fees for specific services not covered in the basic rate readily available?

Does the contract between the resident and the home clearly state:
- costs?
- date of admission?
- services to be provided
- discharge and transfer conditions?

Do the resident's assets remain in his or her control or that of his or her family?

How does the facility assist residents with the safekeeping and management of their funds?

APPENDIX B

NURSING HOME RESIDENTS' BILL OF RIGHTS

The federal government has enacted two bills of rights for nursing home residents: one for skilled nursing facilities and one for intermediate care facilities. The following is a listing of the specific rights included in the two bills. In addition, many states have enacted bills of rights for nursing home residents which provide additional protection and safeguards. Your ombudsman can provide you with a copy of the bill of rights for your state.

FEDERAL BILL OF RIGHTS

Skilled Nursing Facilities

"(1) Is fully informed, as evidenced by the patient's written acknowledgment, prior to or at the time of admission and during stay, of these rights and of all rules and regulations governing patient conduct and responsibilities;

(2) Is fully informed, prior to or at the time of admission and during stay, of services available in the facility, and of related charges including any charges for services not covered under Titles XVIII or XIX of the Social Security Act, or not covered by the facility's basic per diem rate;

(3) Is fully informed, by a physician, of his medical condition unless medically contraindicated (as documented, by a physician, in his medical record), and is afforded the opportunity to participate in the planning of his medical treatment and to refuse to participate in experimental research;

(4) Is transferred or discharged only for medical reasons, or for his welfare or that of other patients, or for nonpayment of his stay (except as prohibited by Titles XVIII or XIX of the Social Security Act), and is given reasonable advance notice to ensure orderly transfer or discharge, and such actions are documented in his medical record;

(5) Is encouraged and assisted throughout his period of stay, to exercise his rights as a patient and as a citizen, and to this end may voice grievances and recommend changes in policies and services to facility staff and/or to outside representatives of his choice, free from restraint, interference, coercion, discrimination, or reprisal;

(6) May manage his personal financial affairs, or is given at least a quarterly accounting of financial transactions made on his behalf should the facility accept his written delegation of this responsibililty to the facility for any period of time in conformance with State law;

(7) Is free from mental and physical abuse, and free from chemical and (except in emergencies) physical restraints except as authorized in writing by a physician for a specified and limited period of time, or when necessary to protect the patient from injury to himself or to others;

(8) Is assured confidential treatment of his personal and medical records, and may approve or refuse their release to any individual outside the facility, except, in case of his transfer to another health care institution, or as required by law or third-party payment contract;

(9) Is treated with consideration, respect, and full recognition of his dignity and individuality, including privacy in treatment and in care for his personal needs;

(10) Is not required to perform services for the facility that are not included for therapeutic purposes in his plan of care;

(11) May associate and communicate privately with persons of his choice, and send and receive his personal mail unopened, unless medically contraindicated (as documented by his physician in his medical record);

(12) May meet with, and participate in activities of social, religious, and community groups at his discretion, unless medically contraindicated (as documented by his physician in his medical record);

(13) May retain and use his personal clothing and possessions as space permits, unless to do so would infringe upon rights of other patients, and unless medically contraindicated (as documented by his physician in his medical record); and

(14) If married, is assured privacy for visits by his/her spouse; if both are inpatients in the facility, they are permitted to share a room, unless medically contraindicated (as documented by the attending physician in the medical record)."

Intermediate Care Facilities

"(a) Information.

(1) Each resident must be fully informed, before or at the time of admission, of his rights and responsibilities and of all rules governing resident conduct.

(2) If the ICF amends its policies on residents' rights and responsibilities and its rules governing conduct, each resident in the ICF at that time must be informed.

(3) Each resident must acknowledge, in writing, receipt of the information and any amendments to it.

(4) Each resident must be fully informed in writing of all services available in the ICF and of the charges for these services including any charges for services not paid for by Medicaid or not included in the

ICF's basic rate per day. The ICF must provide this information either before or at the time of admission and on a continuing basis as changes occur in services or charges during the resident's stay.

(b) Medical condition and treatment.

(1) Each resident must—

(i) Be fully informed by a physician of his health and medical condition unless the physician decides that informing the resident is medically contraindicated;

(ii) Be given the opportunity to participate in planning his total care and medical treatment;

(iii) Be given the opportunity to refuse treatment; and

(iv) Give informed, written consent before participating in experimental research.

(2) If the physician decides that informing the resident of his health and medical condition is medically contraindicated, the physician must document this decision in the resident's record.

(c) Transfer and discharge. Each resident must be transferred or discharged only for—

(1) Medical reasons;

(2) His welfare or that of the other residents; or

(3) Nonpayment except as prohibited by the Medicaid program.

(d) Exercising rights. Each resident must be—

(1) Encouraged and assisted to exercise his rights as a resident of the ICF and as a citizen; and

(2) Allowed to submit complaints or recommendations concerning the policies and services of the ICF to staff or to outside representatives of the resident's choice or both, free from restraint, interference, coercion, discrimination, or reprisal.

(e) Financial affairs. Each resident must be allowed to manage his personal financial affairs. If a resident requests assistance from the ICF in managing his personal financial affairs—

(1) The request must be in writing; and

(2) The ICF must comply with the recordkeeping requirements of Section 442.320.

(f) Freedom from abuse and restraints.

(1) Each resident must be free from mental and physical abuse.

(2) Each resident must be free from chemical and physical restraints unless the restraints are—

(i) Authorized by a physician in writing for a specified period of time; or

(ii) Used in an emergency under the following conditions:

(A) The use is necessary to protect the resident from injuring himself or others.

(B) The use is authorized by a professional staff member identified in the written policies and procedures of the facility as having the authority to do so.

(C) The use is reported promptly to the resident's physician by that staff member.

(g) Privacy.

(1) Each resident must be treated with consideration, respect, and full recognition of his or her dignity and individuality.

(2) Each resident must be given privacy during treatment and care of personal needs.

(3) Each resident's records, including information in an automatic data bank, must be treated confidentially.

(4) Each resident must give written consent before the ICF may release information from his record to someone not otherwise authorized by law to receive it.

(5) A married resident must be given privacy during visits by his spouse.

(6) If both husband and wife are residents of the ICF, they must be permitted to share a room.

(h) Work. No resident may be required to perform services for the ICF.

(i) Freedom of association and correspondence. Each resident must be allowed to—

(1) communicate, associate, and meet privately with individuals of his choice, unless this infringes on the rights of another resident; and

(2) Send and receive personal mail unopened.

(j) Activities. Each resident must be allowed to participate in social, religious, and community group activities.

(k) Personal possessions. Each resident must be allowed to retain and use his personal possessions and clothing as space permits."

In 1987, Congress enacted nursing home reform amendments which will establish stronger protections for residents. These will become effective October 1, 1990. One right under the new law is effective immediately and that is the right to visitation. This includes immediate access to any resident by an ombudsman and the individual's physician. It also includes (with consent of the resident) family, individuals that provide health, social, legal or other services and others who may wish to visit.

APPENDIX C

NURSING HOME STAFF

Federal and state regulations establish minimum standards of care for nursing homes, including what services they must provide to residents, and what personnel they must have to provide these services. Some staffs exceed federal minimum standards and specify staffing ratios or require additional services.

There are two levels of care in nursing homes:

Skilled Nursing Facilities (SNFs) provide 24-hour licensed coverage with supervision from an RN, who is on duty every day, and a medical director. SNF residents require medical or nursing care, or rehabilitation services.

Intermediate Care Facilities (ICFs) provide regular health-related care and services to individuals who do not require SNF care but who, because of their mental or physical condition, require institutional care and services above the level of room and board.

The following is a list of personnel* that nursing homes are likely to have on staff or working as consultants to provide services to residents:

Administrator: a person licensed by the state to administer a nursing home. This individual is ultimately responsible for all nursing home activities. He/she may or may not have special training in psycho-social and medical aspects of aging. Continuing professional education is usually required by the state. In some cases an administrator is also the owner of the facility or a relative of the owner.

***Note:** This list was developed by the National Citizens' Coalition for Nursing Home Reform and is used with permission.

Medical Director: a physician who is supposed to formulate and direct policy for medical care in the nursing home. Medical directors are required only in skilled nursing facilities. Few facilities have full-time medical directors. Facilities may receive waivers for this requirement.

Physician: a person responsible for the residents' medical care. Physicians must visit SNF residents at least every 60 days and ICF residents at least every 120 days.

Director of Nursing: a registered nurse (RN) who oversees the nursing department, including: nursing supervisors, licensed practical nurses, nurses aides, and orderlies. The director of nursing writes job descriptions, hires and fires members of the nursing staff, and writes and executes procedures and policies for nursing practice. Consultations with residents' families, physicians, committees, and community groups are important aspects of the job. The director of nurses is responsible for quality and safety in patient care. (In an ICF, the director of nursing may be an LPN.)

Charge Nurse: RN or LPN in charge of care in a given unit of the nursing home or in charge of nursing care in the absence of the director of nursing.

Licensed Practical Nurse (LPN): one who has completed one year in a school of nursing or vocational training school. LPNs are in charge of nursing in the absence of a registered nurse. LPNs often give medications and perform treatments. They are licensed by the state in which they work.

Nurse's Aide: an employee of a nursing home usually responsible for personal care of the residents (assisting with bathing, feeding, eating, walking, turning in bed, etc.). They work under the supervision of a professional nurse. Although 80–90 percent of nursing home care is provided by aides, generally little training or experience is required. They are sometimes called "Nursing Assistants," "Orderlies" (male), or simply "Aides."

Pharmacist: nursing homes will either have a pharmacy on the premises and a pharmicist on staff, or will contract with a community pharmacy and a pharmacist to provide services. The pharmacist is responsible for supervising the pharmacy program in the home and for reviewing each resident's drug regimen at least monthly.

Social Service Director: a person who is supposed to identify medically related social and emotional needs of residents and provide services necessary to meet them. If the social service director is not licensed or trained, this person must receive consultation from a licensed person. Most often a facility employs a social service director on a consultant basis. Full-time social service directors are *not* required in nursing homes, although the facility is required to provide a social service director's services. Often an activities director "doubles" as a social service director.

Dietary Supervisor: a person trained in planning menus, and regular and special diets, and in establishing dietary procedures. If a dietary supervisor is not licensed, this person must receive consultation from a licensed dietitian.

Activities Coordinator: a person trained in social, recreational or therapeutic programming who provides an on-going program of meaningful activities to promote self-care and physical, social and mental well-being of residents. The coordinator need not be full-time. If he/she does not have professional qualifications, the facility must arrange for consultation by a professionally qualified specialist.

APPENDIX D

Occupational Therapist: a person trained to conduct therapy to maintain, restore, or teach skills to improve manual dexterity and eye-hand coordination. Most often a therapist serves in a part-time or consultant capacity to the facility.

Physical Therapist: a person trained to retain or restore functioning in the major muscles of the arms, legs, hands, feet, back, and neck through movement exercises or treatments. Most often a therapist serves in a part-time or consultant capacity to the facility.

Maintenance and Housekeeping Staff: staff working under the direction of a full-time employee designated responsible for the services and for training of personnel. Personnel provide laundry service, cleaning and maintenance of building and equipment, and cleanliness and safety of the facility.

Medical Records Supervisor: a full-time employee of the facility with responsibility for supervising medical records service. If this employee is not a qualified medical record librarian, the person must function with consultation from someone so qualified.

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

ALABAMA
COMMISSION ON AGING
136 Catoma Street, 2nd Floor
Montgomery, AL 36130
(205) 261-5743

ALASKA
OLDER ALASKANS COMMISSION
Department of Administration
Pouch C-Mail Station 0209
Juneau, AK 99811-0209
(907) 465-3250

ARIZONA
AGING & ADULT ADMINISTRATION
Department of Economic Security
1400 W. Washington Street
Phoenix, AZ 85007
(602) 255-4446

ARKANSAS
DIVISION OF AGING AND ADULT SERVICES
Arkansas Department of Human Services
1417 Donaghey Plaza South
7th and Main Streets
Little Rock, AR 72201
(501) 682-2441

CALIFORNIA
DEPARTMENT ON AGING
1600 K Street
Sacramento, CA 95814
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COLORADO
AGING AND ADULT SERVICES
Department of Social Services
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Denver, CO 80203-1714
(303) 866-5913

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CONNECTICUT
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Hartford, CT 06106
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DELAWARE
DIVISION ON AGING
Department of Health and Social Services
1901 N. Dupont Highway
New Castle, DE 19720
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DISTRICT OF COLUMBIA
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1424 K Street, NW
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Washington, DC 20005
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FLORIDA
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Department of Health and Rehabilitation Services
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Tallahassee, FL 32301
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GEORGIA
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Atlanta, GA 30309
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GUAM
Department of Public Health & Social Services
Government of Guam
Agana, Guam 96910

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Office of the Governor
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Honolulu, HI 96813
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IDAHO
OFFICE ON AGING
Room 114-Statehouse
Boise, ID 83720
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ILLINOIS
DEPARTMENT ON AGING
421 East Capitol Avenue
Springfield, IL 62701
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INDIANA
DEPARTMENT OF AGING AND ADULT COMMUNITY SERVICES
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Des Moines, IA 50319
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KANSAS
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Topeka, KS 66612-1500
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KENTUCKY
DIVISION OF AGING SERVICES
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CHR Building—6th West
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Frankfort, KY 40621
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LOUISIANA
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Baton Rouge, LA 70898
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MAINE
BUREAU OF MAINE'S ELDERLY
Department of Human Services
State House—Station #11
Augusta, ME 04333
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MARYLAND
OFFICE ON AGING
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Baltimore, MD 21201
(301) 225-1100

MASSACHUSETTS
EXECUTIVE OFFICE OF ELDER AFFAIRS
38 Chauncy Street
Boston, MA 02111
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MICHIGAN
OFFICE OF SERVICES TO THE AGING
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Lansing, MI 48909
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MINNESOTA
BOARD ON AGING
Human Services Building, 4th floor
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St. Paul, MN 55155-3843
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MISSISSIPPI
COUNCIL ON AGING
301 West Pearl Street
Jackson, MS 39203-3092
(601) 949-2070

MISSOURI
DIVISION ON AGING
Department of Social Services
P.O. Box 1337
Jefferson City, MO 65102
(314) 751-3082

MONTANA
DEPARTMENT OF FAMILY SERVICES
48 N. Last Chance Gulch
P.O. Box 8005
Helena, MT 59604
(406) 444-5900

NEBRASKA
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NEVADA
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NEW HAMPSHIRE
DIV. OF ELDERLY & ADULT SERVICES
6 Hazen Dr.
Concord, NH 03301-6501
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NEW JERSEY
DIVISION ON AGING
Department of Community Affairs
CN807 South Broad and Front Streets
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Salem, Oregon 97310
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Harrisburg, Pennsylvania 17101-1195
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Department of Social Services
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WISCONSIN
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APPENDIX E

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FLORIDA
STATE LONG TERM CARE OMBUDSMAN COMMITTEE
Department of Health and Rehabilitative Services
Building 1, #308
1317 Winewood Boulevard
Tallahassee, FL 32301
(904) 488-6190

GEORGIA
OFFICE OF AGING
Department of Human Resources
Room 632
878 Peachtree Street, N.E.
Atlanta, GA 30309
(404) 894-5336

HAWAII
HAWAII EXECUTIVE OFFICE ON AGING
335 Merchant Street, Room 241
Honolulu, HI 96813
(808) 548-2593

IDAHO
IDAHO OFFICE ON AGING
State House, Room 114
Boise, ID 83720
(208) 334-3833

ILLINOIS
DEPARTMENT ON AGING
421 East Capitol Avenue
Springfield, IL 62701
(217) 785-3140

INDIANA
INDIANA DEPARTMENT OF AGING AND ADULT COMMUNITY SERVICES
Capitol Center, 251 North Illinois
Indianapolis, IN 46207-7083
(317) 232-7115

IOWA
COMMISSION ON THE AGING
Jewett Building, Suite 236
916 Grand Avenue
Des Moines, IA 50319
(515) 281-5187

KANSAS
DEPARTMENT ON AGING
610 West Tenth Street
Topeka, KS 66612-1500
(913) 296-4986

KENTUCKY
DIVISION FOR AGING SERVICES
Department of Human Resources
275 East Main Street
Frankfort, KY 40601
(502) 564-6930

LOUISIANA
GOVERNOR'S OFFICE OF ELDERLY AFFAIRS
4528 Bennington Avenue
P.O. Box 80374
Baton Rouge, LA 70898-3074
(504) 925-1700

MAINE
MAINE COMMISSION ON AGING
Station 11, State House
Augusta, ME 04333
(207) 289-3658

MARYLAND
MARYLAND OFFICE ON AGING
301 West Preston Street
Baltimore, MD 21201
(301) 225-1083

MASSACHUSETTS
EXECUTIVE OFFICE OF AGING AFFAIRS
38 Chauncy Street
Boston, MA 02111
(617) 727-7273

MICHIGAN
CITIZENS FOR BETTER CARE
1627 East Kalamazoo
Lansing, MI 48917
(517) 482-1297

MINNESOTA
MINNESOTA BOARD ON AGING
444 Lafayette Road
St. Paul, MN 55155-3843
(612) 296-2770

MISSISSIPPI
MISSISSIPPI COUNCIL ON AGING
301 West Pearl Street
Jackson, MS 39203-3092
(601) 949-2070

MISSOURI
DIVISION ON AGING
Department of Social Services
P.O. Box 1337
505 Missouri Boulevard
Jefferson City, MO 65102
(314) 751-3082

MONTANA
SENIORS' OFFICE OF LEGAL AND OMBUDSMAN SERVICES
P.O. Box 232, Capitol Station
Helena, MT 59620
(406) 444-4204

NEBRASKA
DEPARTMENT ON AGING
P.O. Box 95044
301 Centennial Mall-South
Lincoln, NE 68509
(402) 471-2307

NEVADA
DIVISION OF AGING SERVICES
Department of Human Resources
Kinkead Building, Room 101
505 East King Street
Carson City, NV 89710
(702) 885-4210

NEW HAMPSHIRE
NEW HAMPSHIRE STATE COUNCIL ON AGING
6 Hazen Drive
Concord, NH 03301
(603) 271-4375

NEW JERSEY
OFFICE OF THE OMBUDSMAN FOR THE INSTITUTIONALIZED ELDERLY
Room 305, CN808
28 West State Street
Trenton, NJ 08625-0807
(609) 292-8016

NEW MEXICO
STATE AGENCY ON AGING
LaVilla Rivera Building, 4th Floor
224 East Palace Avenue
Santa Fe, NM 87501
(505) 827-7640

NEW YORK
OFFICE OF THE AGING
Agency Building #2
Empire State Plaza
Albany, NY 12223
(518) 474-0108

NORTH CAROLINA
NORTH CAROLINA DEPARTMENT OF HUMAN RESOURCES
Division of Aging
Kirby Building
1985 Ulmstead Drive
Raleigh, NC 27603
(919) 733-3983

NORTH DAKOTA
AGING SERVICES DIVISION
Department of Human Services
State Capitol Building
Bismarck, ND 58505
(701) 224-2577

OHIO
OHIO DEPARTMENT ON AGING
50 W. Broad Street, 9th Floor
Columbus, OH 43266
(614) 466-9927

OKLAHOMA
OFFICE OF CLIENT ADVOCACY
Department of Human Services
P.O. Box 25352
Oklahoma City, OK 73125
(405) 521-2281

OREGON
LONG TERM CARE OMBUDSMAN SERVICES
2475 Lancaster Drive, N.E.
Building B, #9
Salem, OR 97310
(503) 378-6533

PENNSYLVANIA
DEPARTMENT OF AGING
Barto Building
231 State Street
Harrisburg, PA 17101
(717) 783-7247

PUERTO RICO
GERICULTURE COMMISSION
Department of Social Services
G.P.O. Box 11398
Santurce, PR 00910
(809) 722-2429

RHODE ISLAND
RHODE ISLAND DEPARTMENT OF ELDERLY AFFAIRS
79 Washington Street
Providence, RI 02903
(401) 277-6883

SOUTH CAROLINA
OFFICE OF THE GOVERNOR
DIVISION OF OMBUDSMAN AND CITIZENS' SERVICES
1205 Pendleton Street, Room 308
Columbia, SC 29201
(803) 734-0457

SOUTH DAKOTA
OFFICE OF ADULT SERVICES AND AGING
Department of Social Services
Richard F. Kneip Building
700 N. Illinois Street
Pierre, SD 57501-2291
(605) 773-3656

TENNESSEE
COMMISSION ON AGING
715 Tennessee Building
535 Church Street, Suite 201
Nashville, TN 37219
(615) 741-2056

APPENDIX F

STATE AGENCIES ON LICENSING AND CERTIFICATIONS

ALABAMA
DIVISION OF LICENSING AND CERTIFICATION
Alabama Department Public Health
434 Monroe Street
Montgomery, AL 36130-1701
(205) 261-5113

ALASKA
HEALTH FACILITIES LICENSING & CERTIFICATION
Department of Health & Social Services
4041 B Street, Room 101
Anchorage, AK 99503-0333
(907) 561-2171

ARIZONA
HEALTH CARE INSTITUTIONS & LICENSING
Department of Health Services
701 Jefferson Street, 3rd Floor
Phoenix, AZ 85304
(602) 255-1116

ARKANSAS
DIVISION OF HEALTH FACILITIES SERVICE
Arkansas Department of Health
4815 West Markham Street
Little Rock, AR 72205-3867
(501) 661-2201

CALIFORNIA
LICENSING & CERTIFICATION OF HEALTH SERVICES
714 P Street, Room 823
Sacramento, CA 95814
(916) 445-3054

COLORADO
HEALTH FACILITIES REGULATION DIVISION
Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303) 331-4990

CONNECTICUT
LICENSING & CERTIFICATION DIVISION OF HOSPITAL & MEDICAL CARE
Department of Health Services
150 Washington Street
Hartford, CT 06106
(203) 566-1073

DELAWARE
HEALTH FACILITIES LICENSING & CERTIFICATION
Department of Health and Social Services
3000 Newport Gap Pike
Wilmington, DE 19808
(302) 995-6674

DISTRICT OF COLUMBIA
SERVICE FACILITIES REGULATION ADMINISTRATION
DEPARTMENT OF CONSUMER & REGULATORY AFFAIRS
614 H Street, NW, Room 1014
Washington, DC 20001
(202) 727-7190

FLORIDA
OFFICE OF LICENSURE AND CERTIFICATION
2727 Mahan Drive
Tallahassee, FL 32308
(904) 487-2527

GEORGIA
STANDARDS AND LICENSURE SECTION
Room 803, 878 Peachtree Street, N.E.
Atlanta, GA 30309
(404) 894-5137

HAWAII
HOSPITAL & MEDICAL FACILITIES BRANCH
Department of Health
P.O. Box 3378
Honolulu, HI 96801
(808) 548-5935

TEXAS
TEXAS DEPARTMENT ON AGING
P.O. Box 12786 Capitol Station
Austin, TX 78711
(512) 444-2727

UTAH
DIVISION OF AGING & ADULT SERVICES
Department of Social Services
150 W. North Temple, Room 4A
Salt Lake City, UT 84103
(801) 538-3910

VERMONT
VERMONT OFFICE ON AGING
103 South Main Street
Waterbury, VT 05676
(802) 241-2400

VIRGINIA
DEPARTMENT FOR THE AGING
101 N. 14th Street, 8th Floor
Richmond, Virginia 23219
(804) 225-2912

WASHINGTON
SOUTH KINGS COUNTY MULTISERVICE CENTER
1505 South 356
Federal Way, WA 98003
(206) 838-6810

WEST VIRGINIA
COMMISSION ON AGING
State Capitol Complex
Charleston, WV 25305
(304) 348-3317

WISCONSIN
BOARD ON AGING AND LONG TERM CARE
819 North 6th, Room 619
Milwaukee, WI 53203-1664
(414) 227-4386

WYOMING
WYOMING STATE BAR ASSOCIATION
900 8th Street
Wheatland, WY 82201
(307) 322-5553

IDAHO
FACILITIES STANDARDS PROGRAM
Department of Health and Welfare
420 West Washington Street
Boise, ID 83720
(208) 334-4169

ILLINOIS
BUREAU OF LONG TERM CARE
Illinois Department of Public Health
525 West Jefferson
Springfield, IL 62761
(217) 782-2913

INDIANA
BUREAU OF HEALTH INSTITUTION STANDARDS
State Board of Health
1330 West Michigan Street
Room 336
Indianapolis, IN 46206-1964
(317) 633-8442

IOWA
DIVISION OF HEALTH FACILITIES
Department of Inspections and Appeals
Lucas State Office Building
Des Moines, IA 50319
(515) 281-4294

KANSAS
BUREAU OF ADULT & CHILD CARE
Kansas Department of Health & Environment
Forbes Field
Topeka, KS 66620
(913) 296-1240

KENTUCKY
DIVISION FOR LICENSURE & REGULATION
Cabinet for Human Resources
275 East Main Street
Frankfort, KY 40601
(520) 564-2800

LOUISIANA
DIVISION OF LICENSURE & CERTIFICATION
Department of Health & Human Resources
P.O. Box 3767
Baton Rouge, LA 70821
(504) 342-5774

MAINE
DIVISION OF LICENSURE & CERTIFICATION
Bureau of Medical Services
Department of Human Services
State House-Station #11
Whitten Road
Augusta, ME 04333
(207) 289-2606

MARYLAND
OFFICE OF LICENSURE & CERTIFICATION
Department of Health & Mental Hygiene
201 West Preston Street
Baltimore, MD 21202
(301) 225-5430

MASSACHUSETTS
DIVISION OF HEALTH CARE QUALITY
Department of Public Health
150 Tremont Street
Boston, MA 02111
(617) 727-1296

MICHIGAN
HEALTH FACILITIES LICENSURE & CERTIFICATION
Bureau of Health Facilities
P.O. Box 30035
Lansing, MI 48909
(517) 335-8585

MINNESOTA
HEALTH RESOURCES DIVISION
Minnesota Department of Health
717 Delaware Street, SE
Minneapolis, MN 55440
(613) 623-5540

MISSISSIPPI
DIVISION OF LICENSURE & CERTIFICATION
c/o State Department of Health
P.O. Box 1700
Underwood Annex, Room 101
Jackson, MS 39215-1700
(601) 960-7769

MISSOURI
DIVISION OF AGING
Institutional Services Section
P.O. Box 1337
Jefferson City, MO 65102
(314) 751-2712

MONTANA
BUREAU OF LICENSURE & CERTIFICATION
Division of Hospital and Medical Facilities
Department of Health and Environmental Science
Cogswell Building
Helena, MT 59620
(406) 444-2037

NEBRASKA
DEPARTMENT OF HEALTH
Division of Licensure & Standards
301 Centennial Mall-South
Lincoln, NE 68509
(402) 471-2946

NEVADA
BUREAU OF REGULATORY HEALTH SERVICES
Room 202
505 East King Street
Carson City, NV 89710
(702) 885-4475

NEW HAMPSHIRE
DIVISION OF PUBLIC HEALTH SERVICES
Bureau of Health Facilities
Six Hazen Drive
Concord, NH 03301
(603) 271-4592

NEW JERSEY
LICENSURE, CERTIFICATION & STANDARDS
New Jersey Department of Health
CN367
Trenton, NJ 08625
(609) 292-5764

NEW MEXICO
HEALTH FACILITIES & OCCUPATIONAL LICENSURE BUREAU
Health Services Division
Health Environment Department
P.O. Box 968
Santa Fe, NM 87503-0968
(505) 827-2427

NEW YORK
DIVISION OF HEALTH CENTER STANDARDS & SURVEILLANCE
Office of Health Systems Management
State Department of Health
Department H, Room 1895
Corning Building, Empire State Plaza
Albany, NY 12237
(518) 473-3517

NORTH CAROLINA
CERTIFICATION SECTION
Division of Facilities Services
701 Barbour Drive
Raleigh, NC 27603-2008
(919) 733-7461

NORTH DAKOTA
HEALTH RESOURCES SECTION
State Department of Health
State Capitol, Bismark, ND 58505
(701) 224-2352

OHIO
BUREAU OF MEDICAL SERVICES
Ohio Department of Health
246 North High Street
Columbus, OH 43266-0588
(614) 466-7857

OKLAHOMA
STATE COMMISSION OF HEALTH
Department of Health
P.O. Box 53551
Oklahoma City, OK 73152
(405) 271-4200

OREGON
HELATH FACILITIES SECTION
Health Division
1400 SW 5th Avenue, Room 605
Portland, OR 97201
(503) 229-5348

PENNSYLVANIA
BUREAU OF QUALITY ASSURANCE
Pennsylvania Department of Health
Room 907, Health & Welfare Buiding
Harrisburg, PA 17120
(717) 787-8015

PUERTO RICO
HEALTH & SERVICE FACILITIES ADMINISTRATION
Department of Health
P.O. Box 9312
Santurce, PR 00908
(809) 751-0531

RHODE ISLAND
DIVISION OF FACILITIES REGULATION
Rhode Island Department of Health
75 Davis Street
Providence, RI 02908
(401) 277-2566

SOUTH CAROLINA
DIVISION OF HEALTH, LICENSURE & CERTIFICATION
Department of Health & Environmental Control
2600 Bull Street
Columbia, SC 29201
(803) 734-4530

SOUTH DAKOTA
LICENSURE & CERTIFICATION PROGRAM
South Dakota Department of Health
523 East Capitol
Pierre, SD 57501
(605) 773-3364

TENNESSEE
HEALTH CENTER FACILITIES
Department of Health & Environment
283 Plus Park Boulevard
Nashville, TN 37219-5407
(615) 367-6303

TEXAS
QUALITY STANDARDS DIVISION
Texas Department of Health
1100 West 49th Street
Austin, TX 78756-3197
(512) 458-7611

UTAH
FACILITIES SURVEY SECTION
Departmet of Health
P.O. Box 16580
288 North, 1460 West
Salt Lake City, UT 84116-0580
(801) 538-6559

VERMONT
LONG-TERM CARE DIRECTOR
Vermont Department of Health
60 Main Street
Box 70
Burlington, VT 05402
(802) 863-7250

VIRGINIA
DIVISION OF MEDICAL & NURSING FACILITIES SERVICE
Department of Health
James Madison Building
109 Governor Street
Richmond, VA 23219
(804) 786-2082

WASHINGTON
AGING & ADULT SERVICES ADMINISTRATION
Nursing Home Services
623 8th Avenue
Mail Stop HB-11
(206) 753-4465

WEST VIRGINIA
HEALTH FACILITIES LICENSURE & CERTIFICATION DIVISION
West Virginia Department of Health
1800 Washington Street, East
Charleston, WV 25305
(304) 348-0050

WISCONSIN
BUREAU OF QUALITY COMPLIANCE
Wisconsin Division of Health
P.O. Box 309
Madison, WI 53701
(608) 267-7185

WYOMING
DIVISION OF HEALTH & MEDICAL SERVICES
Hathaway Building
Cheyenne, WY 82002
(307) 777-7121

APPENDIX G

SELECTED RESOURCES

If you want to read more about long-term care for older persons, the following references may be useful.

AARP PUBLICATIONS

Making Wise Decisions for Long-Term Care
An overview of long-term care choices. Stock number D12435.

A Matter of Choice: A Guide for Health Care Decisions
Features information about living wills, organ donations, guardianship, and other end-of-life decisions. Stock number D12776.

Before you buy: A Guide to Long-Term Care Insurance
How to select long-term care insurance. Stock number D12893.

Coping and Caring: Living with Alzheimer's Disease
Discusses the nature and symptoms of the disease and coping skills for family and friends. Stock number 12423.

Miles Away and Still Caring
A guide for caregivers living at a distance from their loved ones. Stock number 12748.

A copy of any AARP publication can be obtained free of charge by writing to:

American Association of
Retired Persons
Fulfillment Section
1909 K St., NW
Washington, DC 20049

OTHER PUBLICATIONS

Brody, Elaine M. *Long-term Care of Older People—A Practical Guide*
Human Sciences Press, 72 Fifth Avenue, New York, NY 10011 (1977).

Burger, Sarah Greene and D'Erasmo, Martha. *Living in a Nursing Home: A Complete Guide for Residents, Their Families and Friends*
Crossroad Publishing, 370 Lexington Avenue, New York, NY 10017 (1976).

Department of Health & Human Services, Health Care Financing Administration, *How to Select a Nursing Home*
6325 Security Blvd., Baltimore, MD 21207

Hooyman, Nancy R. and Lustbader, Wendy. *Taking Care—Supporting Older People and Their Families*
The Free Press, New York (1986).

MacLean, Helene. *Caring for Your Parents—A Sourcebook of Options and Solutions for Both Generations*
Doubleday & Company, Inc., Garden City, NY (1987).

Rossi, Ted. *Step by Step—How to Actively Ensure the Best Possible Care for Your Aging Relative*
Warner Books Inc., 666 Fifth Avenue, NY 10013 (1987).

ORGANIZATIONS

Alzheimers Disease & Related Disorders Assn., 360 N. Michigan Avenue, Chicago, IL 60601

American Association of Homes for the Aging, a membership association comprised of non-profit nursing homes, retirement centers and facilities for independent living, 1129 20th St. NW, Washington, DC 20036.

American Health Care Association, a membership association of providers of nursing home care, 1201 L St. NW, Washington, DC 20005.

National Citizens Coalition for Nursing Home Reform, an association comprised of individuals and agencies concerned with the quality of life of nursing home residents, 1424 16th St. NW, Suite L-2, Washington, DC 20036.

National Senior Citizens Law Center, 2225 M Street NW, Washington, DC 20036.

With more than 27 million members, the American Association of Retired Persons is the nation's largest nonprofit, nonpartisan organization of Americans age 50 and older. AARP offers a wide range of membership benefits, legislative representation at federal and state levels, and educational and community service programs which are implemented through a national network of volunteers and local chapters.

Health Advocacy Services
Program Department

AARP

American Association of Retired Persons
1909 K Street, N.W.
Washington, DC 20049

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